



Helping Families Have The Most Difficult Conversation

December 28, 2013

[Listen to the Story](#)

[Weekend Edition Saturday](#)

5 min 51 sec

- [Playlist](#)
- [Download](#)

The Conversation Project is encouraging families to discuss their end-of-life preferences before it's too late. Founder Ellen Goodman speaks with NPR's Linda Wertheimer about helping people initiate these conversations, and why they are so important.

LINDA WERTHEIMER, HOST:

This is WEEKEND EDITION from NPR News. I'm Linda Wertheimer. I hope that most of the people listening to us today have been with their families and friends during this holiday season. We've all had nice dinners and nice talks, but maybe there is one more talk we ought to have and the subject maybe won't sound quite right for the holidays.

But perhaps there is no better time. We ought to be talking about death. My old friend, Ellen Goodman, is the person who's raised this with me and others. She was a journalist and Boston Globe columnist for many years. She's now trying to organize families to face a tough issue. She's named this effort The Conversation Project. She's trying to help people find a way to talk about a subject we've all been brought up to avoid.

Ellen is at our member station WGBH in Boston. Ellen, thank you for doing this.

ELLEN GOODMAN: My pleasure. Thank you.

WERTHEIMER: Now I understand that this comes out of your own personal experience.

GOODMAN: It does. When I went through the experience of my mother's last months and actually years, there were all kinds of decisions that I had to make for which I was totally unprepared and which my mother and I hadn't talked about. And we were people who talked about virtually anything. And that experience was really very unsettling.

WERTHEIMER: And if you had had that chance, taken that chance, to talk to her about it, you might not have even done anything very differently, but you would have sort of known where you were.

GOODMAN: I think we've learned that when people do have these conversations with the people they love, they experience less depression, less sorrow, less guilt afterwards. So, The Conversation Project is not only for people to express their wishes, but it's for their survivors.

It's for their families. That's why it's a rich family conversation, even at the holidays, when, I know, it sounds counterintuitive.

Merry Christmas, Happy New Year, and now let's talk about dying. But in fact, these conversations may be among the richest and most intimate that we'll ever have.

WERTHEIMER: I raise the same kind of issues with friends, maybe 20 years ago at a college reunion. You know, we were going around the circle saying everybody, if you have some important advice, now is the time. And I said you have to figure out how to handle the death of your parents because my mother died young and I was totally not ready. I wonder why this is such a difficult issue for families just to really face.

GOODMAN: Well, it's tough stuff. You're talking about loss. We have found though that these conversations between, say, adult children and elderly parents, where very often the elderly parents don't want to worry their children and the children don't even want to suggest to their parents the remote possibility that they're going to die. But everybody knows it. My favorite line about this was the headline in the Onion, the online satirical magazine, that said, you know, death rate holds steady at 100 percent.

So it's not a secret, but that fact that we don't talk about it can leave us feeling very lonely and uncertain about what to do when we're faced with decisions.

WERTHEIMER: I know that I said to my mother, we don't need to talk about this; you're going to be fine. And afterwards I'm kicking myself all around the place for having prevented her from telling me what she wanted.

GOODMAN: I think that's what so many of us do. And what we don't want our families and the people who will survive us to feel is that kind of regret. Our survey said that 90 percent of people know it's important to have these conversations and only 30 percent are having them. So how do you close the gap?

WERTHEIMER: In your typical practical way, Ellen, what you've done is you've created a workbook basically for dealing with the conversation and in very early on, you get right down to cases. You want people to think about what they want at the end of their lives. And on the page that you call get set, the second question is finish this sentence. What matters to me at the end of life is....Why is that an important thing to find out?

GOODMAN: Well, in general, what we wanted to do was not to create a starter kit that said, you know, if my left elbow and my right eyebrow are gone, you know, pull the plug. That's not really useful. And it's scary. We wanted people to talk about what values, we wanted them to talk about what matters to them and not what's the matter with them. And some of the most common responses are peacefulness, comfort, being surrounded by people we love.

Seventy percent of Americans say they want to die at home, but 70 percent are dying in hospitals and institutions. And dying at home is not necessarily a geographical place, but it's an idea, and we have to share that idea with the people that we love who may be making decisions for us.

The other reason to have it, of course, at the holiday season when people are around is you don't want your children or the people who may be making decisions for you to get into a disagreement. You want them all to know what it is that's important to you.

WERTHEIMER: When will you know that this Conversation Project has worked - has taken hold?

GOODMAN: I think will know that The Conversation Project has succeeded in that sense, when people ask each other: Have you had the conversation? And they know the answer, and the answer is yes.

WERTHEIMER: Ellen Goodman founded The Conversation Project. She joined us from member station WGBH. Ellen, thank you very much.

GOODMAN: Thank you, Linda.

Copyright © 2013 NPR. All rights reserved. No quotes from the materials contained herein may be used in any media without attribution to NPR. This transcript is provided for personal, noncommercial use only, pursuant to our Terms of Use. Any other use requires NPR's prior permission. Visit our permissions page for further information.

NPR transcripts are created on a rush deadline by a contractor for NPR, and accuracy and availability may vary. This text may not be in its final form and may be updated or revised in the future. Please be aware that the authoritative record of NPR's programming is the audio.