

Beginning To Talk About The End

Q: Any tips for having a discussion about End-Of-Life Care?

A: Most people feel uncomfortable talking about dying---or what kind of care they would like at the end of their life. A new group, called The Conversation Project, believes that the time to talk about end-of-life care is at the kitchen table, not in the intensive care unit. “Too many people are dying in a way they wouldn’t choose,” The Conversation Project says, “and too many of their loved ones are left feeling bereaved, guilty, and uncertain.” The Conversation Project wants to make sure that our own wishes and preferences are talked about openly, and respected.

According to a survey conducted in California, 60% of people say that making sure their family is not burdened by tough end-of-life decisions is “extremely important,” yet 56% have not told their family about their end-of-life wishes. The same survey revealed that less than one in four people had put their wishes in writing. One federal surveyed found that 70% of people would prefer to die at home, yet 70% die in a hospital or nursing facility.

The Conversation Project began in 2010, when a group of medical professionals, clergy, and members of the media began sharing stories of “good deaths” and “bad deaths” within their own circle. From there they began a grassroots public campaign with the ambitious goal of “changing our culture” to make it easier to talk about dying, and “to encourage people to talk now and as often as necessary so that their wishes are known when the time comes.”

For people not sure how to begin this discussion with loved ones, The Project has published a “Your Conversation Starter Kit,” designed to help you get your thoughts

organized. The Starter Kit asks questions like: How long do you want to receive medical care? How involved do you want you loved ones to be? Do you think that your loved ones know what you want, or do you think they have no idea?

The Kit also suggests some things you could say to “break the ice” about end of life care: “I need to think about the future---will you help me?” “Even though I’m ok right now, I’m worried about what might happen to me---and I want to be prepared.” The Kit also suggests you talk about how actively you want to be involved in decision-making about your care, and who you would like to be your health care proxy? Do you want (or not want) aggressive treatment, like resuscitation, feeding tube, etc?

According to The Conversation Project, you don’t have to try to guide the conversation---just let it happen. And every attempt at a conversation is valuable. These conversations are meant to help you and your loved ones live and die in a way that you choose.

Every family has stories to tell about how some loved one died—after a long illness, or perhaps suddenly. We talk about ‘good deaths’ and ‘bad deaths,’ but in many of these situations, it is not clear how and where the loved one wanted to die, and what specific instructions they would have wanted the family to use as a guide.

To learn more about The Conversation Project, and to print out a copy of Your Conversation Starter Kit, go to www.theconversationproject.org, and be sure to print out the document called “How to talk to your doctor.”