

JOANNA WEISS

## Can we talk about death?



By Joanna Weiss | GLOBE COLUMNIST | DECEMBER 26, 2014

HERE'S A goal for 2015: Can we re-make death the way we re-made birth?

Think about it: Only decades ago, most American women gave birth alone in hospital rooms, without family members present, sometimes drugged to the point that they didn't even remember the experience. Thanks to activism and public awareness — some of which started with the Boston-based women's movement — the experience of birth has been largely reclaimed. Some women write birth plans, hire doulas, turn on the cameras, do the whole thing at home with their older kids nearby. Some hew to the comfort of a hospital bed and embrace the epidural. And yes, there are still judgments made and questions asked, but we at least accept that everyone has choices.

“Birth is not just a medical experience. It's a human experience,” Ellen Goodman, a former Globe columnist, was telling me recently. “What we're saying is that dying is not just a medical experience. It's a human experience.”

Since she left her regular column five years ago, Goodman has taken up this cause. She co-founded [The Conversation Project](#), a public-awareness campaign that works, with the Institute for Healthcare Improvement, to get people thinking and talking about end-of-life choices — for the sake of saving money, reforming health care, and giving families comfort and peace.

It has been a slow process; we are stubbornly reluctant to confront our own mortality. A Conversation Project survey, conducted last year, found that while 90 percent of Americans think it's important to talk with relatives about end-of-life decisions — to gauge our personal preferences, while we're able to share them — only 30 percent have had the conversation.

But Goodman thinks we might be on the verge of a moment. Atul Gawande's “Being Mortal: Medicine and What Matters in the End” has been a bestseller for months. In September, the Institute of Medicine released a [report](#) called Dying in America, which calls for improvements to end-of-life care. New Massachusetts regulations call for doctors to offer end-of-life counseling to terminally-ill patients. And of course, there was Brittany Maynard, the 29-year-old brain cancer patient whose death in November, via physician-assisted suicide, got plenty of people thinking about hard choices.

Maynard's very public death helped raise awareness of one particular way of dying, but it struck some people badly. After I [wrote](#) about her last fall, one commenter on the Globe's website objected, passionately, to use of the term “Death With Dignity.” She asked: What of her brother

and father, who chose to die in hospice care, and needed help with their bodily functions in the end? Were they being “undignified”? Were they lesser for having been burdensome? Were people suggesting that suicide is the preferable path?

I don’t know what the fiercest advocates would say, but if we do this correctly, there will be no right or wrong choices. The point is that there are choices — which is where Goodman’s conversations come in.

Her group’s big contribution is a “Conversation Starter Kit.” It went online on the group’s website in 2012 and has been downloaded more than 150,000 times. Goodman said that people are holding onto them like “a security blanket.” “It reminds me a little of the personality quiz books my 10-year-old daughter loves – favorite animals and colors – except that the topics are weighty: Where would you want to have a conversation about death? How much do you want to know about your end-of-life medical care? Would you want to be surrounded by your loved ones in the end? Do you want to have an active role in your care, or have doctors do what they think is best? Are there milestones you’d want to live for? Certain kinds of treatment you would want, or wouldn’t want?

Think of it as a kind of grown-up slumber party activity and it feels a little easier to handle. The conversation is bound to be intimate and meaningful. The hard part is getting started. So Goodman’s group, in conjunction with a separate West Coast-based campaign called “Death Over Dinner,” has proposed a way to jump-start the process: a week of dinner parties, held from January 1-7, under jarringly-cheerful banner “Let’s Have Dinner and Talk about Death!” They’re asking people to register, download those kits, and talk.

A cheery conversation about mortality? It’s hard to fathom. But then, it once was hard to imagine a different way to start life too.

*Joanna Weiss can be reached at [weiss@globe.com](mailto:weiss@globe.com). Follow her on Twitter [@JoannaWeiss](https://twitter.com/JoannaWeiss).*