A Conversation on the art of dying

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November 19, 2014

I am inside this grand, imposing, dark-wood-paneled room at the equally imposing Harvard Divinity School, Cambridge, at a dinner about death.

It’s a subject I seem unable to escape since taking on the religion beat.

There’s about 20 of us - Catholics, Muslims, Jews, Buddhists, Unitarians, Episcopalians, one woman of no defined faith, even a Spiritualist. We’re eating lasagna and macaroni and cheese, ideal comfort food for such a nerve-shattering discussion.

Why are we dining with death? Because The Conversation Project, co-founded in 2010 by former Boston Globe columnist Ellen Goodman, is picking up steam across the country. Tonight, yet another group of future religious leaders will learn what it’s about: Encouraging end-of-life care conversation with parents, children, spouses, siblings, etc., before they’re at death’s door. The hope is to increase the chance of a good death while decreasing anxiety among families unsure of what their dying loved one would’ve wanted. Now they know.

Volunteers give us The Conversation Project Starter kit. Among its many questions:

- What matters to you at the end of life is? (Fill in the blank).
- Do you want to live as long as possible, no matter what?
- Do you want make decisions about your care, or have doctors and family do it for you? To know everything there is to know about your prognosis, or to live in ignorant bliss?

According to The Conversation Project, 70 percent of us say we’d prefer to die at home. But 70 percent of us do not. More than 90 percent of us think it’s important to talk about our own and loved ones’ wishes for end-of-life care. Less than 30 percent of us actually do.

It turns out end-of-life talks are like birds-and-bees talks. We know we should have them. We don’t.

And I get that. Part of me thinks having The Conversation will somehow jinx me, speed things up. Conversation today, dead tomorrow.

Apparently I’m not the only one with ridiculous superstitions, says Rosemary Lloyd, The Conversation’s liaison to the faith-based community.

There are lots of superstitions about death. And denial and dread and family in-fighting. Until The Conversation, I’d not heard of “seagull” in the end-of-life context. That’s the name for the know-it-all son or daughter who so often flies in at the very last minute and then tries to take over mom or dad’s care from the son or daughter who’s done it all for years.
Ellen Goodman says that during her own mother’s struggle with dementia, she was bewildered by endless decisions and upset about not knowing what her mother would’ve wanted.

In a telephone interview after the dinner, Goodman said that’s why she started the project. She’s already had The Conversation with her own daughter who was not - and this is typical - enthusiastic. “But people who are reluctant report back that these conversations were among the richest they ever had in their family.”

And, in fact, once we start talking death at the divinity school dinner, even among strangers, it gets fascinating fast. One woman says she can’t even think about her mother dying, never mind about washing her body in preparation for burial, a Muslim ritual. I tell about my grandfather’s three-day wake in my childhood home, and how I snuck in at night to poke his cold hand. I was 9. A project volunteer, who barely looks old enough to drink, has nonetheless figured out what she’d like around her own death bed: pretty, airy, colorful things. Flowers, lots of light.

Once upon a time, says Rosemary Lloyd, there was something called the Ars Moriendi (“art of dying”), a practical death instruction book for Christians popular hundreds of years ago. Today we don’t have such a manual. We don’t learn how to manage death. So doctors, hospitals, and funeral homes manage it for us. Lloyd considers The Conversation like an updated version of the Ars Moriendi, instructions on how to reclaim the sacredness and family intimacy of death.

“I had the conversation with my own grandfather and it made a difference,” she says. “He was about 85. I was a young mother living 7 or 8 hours away. One day I said, ‘Grandpa, I’m worried when I leave I may never see you again.’ ‘Don’t worry,’ he told me. ‘I’m an old man and I’m not afraid to die. I’ll see you, and if I don’t see you, I’ll see you.’ That became our joke. At the end of every visit one of us would say, ‘I’ll see you,’ with special meaning.”

Eleven years passed. She was home visiting. Her grandfather, a retired caretaker, had spent the day transplanting a fig tree, cleaning his tools, enjoying a family dinner. “In the middle of the night I heard him call out, saying he was cold and he can’t get up.” She and her mother are both nurses. They came into his room and quickly understood. He was close to death.

Her panicked father wanted to call 911. But Lloyd explained what the EMTs would have to do. It would not be pleasant. It might be painful. They’d have to take him away, in the night, to the hospital. Then she explained her conversation with her grandfather about dying and told her father, “Just come be with him.”

“Then it was like a movie,” Lloyd says. Her father and his two brothers came and gathered around her grandfather’s bed, held his hand, and touched his face as he took his final breath. He wanted to die peacefully, with his family, in his own bed, in his own home. And he did.

For more information, visit TheConversationProject.org.