

# Planning for the Inevitable: *End-of-Life Discussions*

By Jessie Sholl / November 2013

**Ellen Goodman**, columnist at the Boston Globe, was working on a deadline when she got a call from the nursing home staff caring for her mother. Her mom was in decline with dementia and had already received a raft of medical interventions; now a nurse wondered if she should administer antibiotics for a life-threatening bout of pneumonia. Having never spoken in detail with her mother about how much treatment she wanted to endure, Goodman realized how ill prepared she was for the situation. Her sister was no better equipped, and it was too late for their mother to make her desires clear.

Moments like these are all too common. End-of-life decisions are a universal human experience, but few of us want to bring it up in conversation, much less talk about their consequences. We're afraid to sound rude, or morbid, or — when dealing with a terminally ill person — like we're in a hurry for someone to die. As a result, too many of us are left to make life-or-death decisions for loved ones without their guidance.

There's no question that discussing end-of-life planning is challenging, but it's worth the effort. Such conversations can lead to greater peace of mind for all parties, a more peaceful passing, and a cementing of emotional bonds.

Here are a few ideas for how to open the door on this touchy topic — and what to do once you've walked through.



## Face Your Fears

Hindu people have been gravitating to the northeastern Indian city of Varanasi for millennia — the living to make pilgrimages, the dead to be cremated and scattered in the sacred waters of the River Ganges. Funerals are not necessarily somber, and people believe if you're lucky enough to be cremated in Varanasi, nirvana is yours.

Western cultures tend to have a less sanguine attitude toward death. We often fall prey to the superstitious belief that discussing death will summon it, which makes advance planning a particular challenge. Consider the Affordable Care Act's tumultuous journey into law in 2010. The suggested provision to reimburse doctors who discussed options for end-of-life plans with patients was targeted by critics as evidence of "death panels."

Laura Semmler, the executive director of Mission Hospice in San Diego, says she commonly watches patients struggle with similar superstitions. People worry that putting end-of-life plans in place means that those involved have given up hope, or that writing up an advance medical directive automatically means ceding control over all life-and-death decisions.

According to Jane Brody, New York Times health columnist and author of *Jane Brody's Guide to the Great Beyond* (Random House, 2009), preparing for certain contingencies doesn't mean all decisions are set in stone — particularly those that involve life support. "As long as you are alert, and cognitively together, you can say at any point, 'I want a feeding tube, I don't want a feeding tube,'" she points out. "Your advance directive comes into play only when you're unable to make those kinds of decisions yourself."

In most cases, end-of-life planning is simply an acknowledgement that none of us is going to live forever. If we're interested in having some control, our best choice is to accept death's eventuality, take care of ourselves, hope that the end is far in the future, and plan for it nonetheless.

**How do you start when no one wants to talk about it? As with most things you're doing for the first time, find help.**

## Start the Conversation

After her mother died, Goodman assembled a team and met with media, healthcare practitioners, and clergy in the Boston area to explore the way people deal with death (or don't) in the United States. She wanted to open up a dialogue so others wouldn't face the same situation she and her sister had faced. In 2010 she founded The Conversation Project with her colleagues. The initiative is designed to encourage discussions about end-of-life planning so people can make decisions for themselves and their families at the kitchen table — rather than in the intensive care unit.

The Project now hosts a website ([www.theconversationproject.org](http://www.theconversationproject.org)) featuring resources designed to help overcome awkward details: sample letters to family, guiding statements to help establish preferences (“What I want at the end of my life is . . .”), as well as talking points for the conversation itself. There are even filmed discussions between family members that demonstrate how addressing end-of-life concerns can be a powerful tool for building closeness.

One of the clips features a father telling his son that at the end he wants no lifesaving measures of any kind. The son doesn't understand the request until he learns that his father's first wife died from breast cancer at 23, under the worst medical circumstances. Until that talk, in fact, the son didn't even know that his father had been married before.

## Do the Paperwork

Once the door is open, it's easier to address practical concerns directly. Every individual and family has different legal and spiritual needs, but certain items pertain to most everyone:

If you have life insurance, reexamine the policy to make sure you're still satisfied with the coverage.

An advance directive outlines your preferences for medical care should you become unable to make your own decisions. It also allows you to name a healthcare proxy who can make decisions on your behalf. The paperwork varies by state (even the title can vary); the forms for each state can be found on the Caring Connections website ([www.caringinfo.org](http://www.caringinfo.org)). Be sure to tell at least one person that you've prepared a directive. Give copies to loved ones or make sure they know where you've stored it.

Wills can be simple — completed online in a few hours — or more complicated, depending on your circumstances. While such a document might not seem essential, do consider one, even if you're not leaving behind a mass of wealth. A will is a simple way to ensure that your money, property, and personal belongings will be distributed as you wish after your death. Without one, most states' inheritance laws will control how your estate is divided.

## Breathe a Sigh of Relief

“We prepare for all sorts of things,” Brody says. “We prepare for tests; we prepare for medical exams, school, applications for jobs and college. This is just part of sensible preparation.”

The impact of having plans in place can't be overstated. While researching her recent book, Brody says, she saw firsthand the profound emotional distress on families having to make end-of-life decisions without any direction. “The loved ones are more likely to end up with complicated grief,” she says.

She also saw how to achieve the opposite. When people have come to terms with the fact that they will die eventually, she says, and they've made detailed arrangements, their families are able to be completely present in the end. Whether loved ones are appreciating each other's company or making important amends, this time is precious. Not having to second-guess medical decisions, Brody says, leaves people free to focus on what really matters — each other.

Martha Hayward, who is in charge of patient engagement for The Conversation Project, concurs. “Feeling cared for and having people around you who understand and love you enough to do what you wish, despite their possible reservations, is an enormous comfort for the person dying, and it comforts the loved ones in knowing that they're doing the right thing.”

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