



IN THE ARENA

Death Panels: An Obituary

On January 1, Obamacare starts paying for end-of-life conversations, and a scare story finally dies.

By ELLEN GOODMAN | 12/30/2015

This is the moment in the year when we assess the past, bid farewells and wipe our slates clean. 2015 may well go down as a year of demagoguery, or Trump-agoguery, if you prefer, in which no lie was so blatant it couldn't enhance a politician's popularity.

That said, let us raise a glass to one piece of outrage that was actually buried.

I give you an obituary for "death panels."

Remember death panels? The saga began in 2009, when a provision in President Barack Obama's new health care bill proposed that doctors be paid for time spent having conversations with patients planning for end-of-life care. Betsy McCaughey, former lieutenant governor of New York, was the first to magically transform these voluntary talks into mandatory sessions

that would tell seniors “how to end their life sooner.” But it was Sarah Palin, with her gift for disinformation, who renamed these talks death panels.

In rapid order, death panels became the star of cable news, politicians dove under their desks, and there was rabid talk about a government plan to pull the plug on grandma. PolitiFact called this the “lie of the year” in 2009, since there was nothing in the bill that would limit care, or create a government panel. But Palin and her Facebook friends had won the framing exercise. The proposal was deleted from the plan and then later from regulations, and anything to do with “end of life” became the third rail of health care policy. A few champions, like Earl Blumenauer (D-Ore.) remained stalwart, but the administration went silent. As one policymaker in the administration described it, “It was a group tongue-biting exercise.”

Fast forward to this season’s greeting. In July, Medicare put forward nearly the same proposals for public comment. They sailed through with barely a ripple of protest. Starting January 1, doctors and other clinicians will be paid a modest fee for the time spent discussing patient’s preferences for the treatment they want in their last days. What happened? How did truthiness—or truthlessness—go down? How did the frame collapse?

It turns out that sometimes, yes, people’s life experiences trump political posturing. Sometimes the culture changes and creates a new frame. We go from hyperbole to reality.

These past five years have been a time of remarkable transformation. The old taboo against talk of death is gradually lifting. There’s a growing movement to encourage the most important conversation too many Americans still aren’t having.

I’ve seen that change up close. In 2010, at the height of the death panel flare-up, a small group of us—doctors, media, clergy—had just begun meeting in Boston. I helped begin this in the aftermath of my mother’s death, when I was overwhelmed, indeed stunned, by the decisions that had fallen to me. I often wished that I could hear her voice, telling me what she wanted.

At our first gathering, we took off our professional hats and shared similar stories of the loss of people we loved. We all talked about being faced with a cascading number of decisions for which we felt unprepared. We talked about good deaths and hard deaths. The difference, it often seemed, was whether we had known what our loved ones wanted.

We began to think about how we could make this easier for ourselves and the people we loved. We began to call ourselves simply “The Conversation Project,” and to envision a public engagement campaign to see that people’s wishes for end-of-life care were expressed and respected.

That spring, the Institute for Healthcare Improvement, which was then led by Don Berwick, invited a group of experts in end-of-life care to meet with us. Dr. Berwick had just been picked by the president to head the Centers for Medicare & Medicaid Services, but the atmosphere around this issue was so toxic that he literally couldn’t join us in the meeting room.

His successor, Maureen Bisognano, led a gathering with 30 experts who’d worked for decades to change end-of-life care and were deeply frustrated. Too many people were not dying in the way they would choose. Too many survivors were left guilty, depressed, uncertain that they had done the right thing.

What we needed, they agreed at the end of the day, was to go outside the health care system and change the culture. We needed to change the norm from avoiding conversations about how we want to live at the end of life, to talking about it.

Once you open the door to talking about it, it often seems that everyone has a story. In my half a century as a journalist, I've never encountered an issue like this. When I talk about this with someone, there is half a beat and then it begins to pour out. Many people's stories have been locked away for years, but they carry deep emotional resonance. As experiences are shared, we know we're not "the only one."

Since 2010, a growing number of people and organizations have begun working in and out of the health care system to encourage talking about end of life preferences.