

Thoughtful Endings
Sunday November 8, 2015

Dick van Dyke may not be tripping over ottomans anymore, but he's still singing, dancing, and, these days, talking about his new book: *Keep Moving and Other Tips and Truths About Aging*. He'll turn 90 next month, so clearly he knows something about aging. I heard him interviewed by Diane Rehm a few weeks ago, and was especially struck by a conversation with Carl Reiner which he reports in the book. Carl Reiner created and directed *The Dick Van Dyke Show* back in 1961 and the two men have been friends ever since. Carl Reiner is a little older – 93. As they talk about aging and slowing down, Dick van Dyke tells Carl Reiner “I still have vivid dreams of myself running across an open field, like a deer – that freedom.

Carl: That's a good dream. I dream all the time. I have to remember them because I go to a psychiatrist once a week and try to figure out what they're about.

DvD: You're still in therapy?... After all these years, what are you still working on?

Carl: Anxiety.

DvD: What is causing you anxiety?

Carl: Dying.”

Dick van Dyke plays this exchange for laughs, and laugh we do, but for many of us, the laughter isn't caused by our surprise that someone of Carl Reiner's age is still worried about death, but because we share his anxiety. Either for our own deaths or those we love, we worry and fear. And often we deal with our anxiety by avoiding the subject completely. We don't want to have “the conversation.”

It's not like I went around telling people about the topic of this sermon this week, but all of a sudden my conversations were filled with stories about the avoidance of these end-of-life conversations. A friend, whose 40-something husband is dealing with a life-threatening condition, was telling me about their conversations and how relieved she is that they are talking about what matters, because her brother-in-law, who died in his 30's after an illness of several years, was never able to have these conversations with his wife, her sister. She said, “They both went to his appointments and knew the prognosis, but they never once talked about the fact that he was going to die or what he wanted.” Two years

after his death, her sister and the children are still dealing with unresolved emotional and financial issues. Another person this week talked with me about how not only are her parents in their 80's unwilling to talk about hopes, fears, or plans for their future, they also are not able to talk about plans for her older sister who is disabled and still lives with them.

Perhaps they've been waiting for their family physicians to raise these questions with them, but doctors often haven't been trained in these conversations any more than lay people have. In his book *Being Mortal*, Atul Gawande tells the story of Joseph Lazaroff, a patient with incurable prostate cancer. Despite that, his medical team tried many treatments including emergency radiation and surgery. The one thing they didn't try was talking with Mr. Lazaroff about what he wanted. Gawande wrote, "We could never bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter most to him as he neared the end of his life. The chances that he could return to anything like the life he had even a few weeks earlier were zero. But admitting this and helping him cope with it seemed beyond us."

After seeing the need for these conversations, it's no wonder that Dr. Gawande is now an advisor to The Conversation Project. The Conversation Project was founded three years ago by Ellen Goodman, the Pulitzer Prize-winning Boston Globe columnist, after the deaths of her parents. In an article this summer in *The New York Times*, she remembered why their deaths persuaded her that a program to encourage end-of-life conversations was needed. She wrote,

"I was 25 when I flew home for my father's last birthday. His cancer had returned and he would die three months later at the age of 57. What I remember most about that weekend was the large rectangular gift box he opened. My mother had bought him a new suitcase.

.... I have never forgotten that image and how we lost a chance to say goodbye. I still wonder if my father was lonely in the silence that surrounded our inability to talk about what we all knew.

Decades later my mother began a long slow decline. ...[M]y mother and I talked about everything — but we didn't talk about how she wanted to live toward the end.

Gradually and painfully, my mother lost what the doctors call "executive function," as if she were a C.E.O. fumbling with Excel spreadsheets, not a 92-year-old who couldn't turn on the television or make a phone call. Eventually, she couldn't decide what she wanted for lunch, let alone for medical care.

In some recess of my mind, I still assumed that death came in the way we used to think of as “natural.” I thought that doctors were the ones who would tell us what needed to be done. I was strangely unprepared, blindsided by the cascading number of decisions that fell to me in her last years.

I had to say no to one procedure and yes to another, no to the bone marrow test, yes and yes again to antibiotics. How often I wished I could hear her voice in my ear telling me what she wanted. And what she didn’t want.

When my mother died ..., I began to talk with others. It was extraordinary. Everyone seemed to have a piercing memory of a good death or a hard death. Some of these stories had been kept below the surface for decades, and yet were as deep and vivid as if they’d just happened.

Too many people we love had not died in the way they would choose. Too many survivors were left feeling depressed, guilty, uncertain whether they’d done the right thing.

The difference between a good death and a hard death often seemed to hinge essentially on whether someone’s wishes were expressed and respected. Whether they’d had a conversation about how they wanted to live toward the end.”

Today, along with religious congregations of many faiths, we are observing the Conversation Sabbath, a time to encourage one another to have these conversations.

In my own family I’ve seen the difference this conversation can make. In 1996 when she was 62 my mother developed a rash which eventually led to a diagnosis of inflammatory breast cancer. But though she accepted treatment for the cancer, she never acknowledged that she had the disease – it was just a rash, she insisted, and since, in her logic, she didn’t have cancer, there was no reason to discuss end-of-life care. We had no idea what her wishes were. She died at Mass General in 1998 surrounded by family and friends, but so medicated we weren’t sure she knew we were there.

Twelve years later when my father developed a choking cough, he called me and my sister right away to let us know that he’d been diagnosed with esophageal cancer. Having learned from our experience with my mother’s illness what not to do, my father knew he needed to be open about what was happening and what was important to him. He sent regular e-mail updates to family and friends about his treatments and how he responded to them and also reflected in those letters on the pleasures he took in his children, grand-children, and new wife. After two

years when the experimental treatment he was offered at Dana Farber stopped being effective, his oncologist talked with him about his wishes, connected him with hospice, and kept in touch with him through his remaining days. He died at home, with his family singing to him, telling stories, and toasting him with his good wine. Not long before he died, he echoed his minister Forrest Church's words, telling my sister and me that he was ready to die but would miss knowing what would happen in his grand-children's lives. "It's like I started reading a good story, and am putting the book down unfinished," said the English major. But thanks to his ability to talk with us, his chapter in our lives closed sadly but without the emotional pain and anger of my mother's death.

That's the difference this conversation can make – not just in the life of the person who is dying but in the lives of those left behind. As Ellen Goodman wrote, "When I helped found the Conversation Project, I thought we were doing this for people who were dying. I thought of my parents...What I have learned is that the conversation is also a legacy. This is the gift, maybe the last gift, we can give one another." Or as a participant in one of the conversations put it, "Now I understand. The conversation is a gift to your family."

So how do we have these conversations to make sure that our stories end in the way hoped? I came across a number of helpful resources while working on this sermon: The Conversation Project brochure the ushers handed out offers ways to bring the topic up with family members. Their starter-kit offers tools to help you think about what you value, how you would like to be treated by doctors, how involved you'd like your family and friends to be, and where you'd like to spend your last days. You can fill out the form and show it to your family and your doctor. Copies are on the table at the back and also available at their website.

The Five Wishes offers another tool – it invites you to write down your wishes on these five topics:

- The Person I Want to Make Care Decisions for Me When I Can't
- The Kind of Medical Treatment I Want or Don't Want
- How Comfortable I Want to Be
- How I Want People to Treat Me
- and What I Want My Loved Ones to Know

In addition to health care considerations, it invites you to think about what you'd like for a memorial service.

The most fun tool I found – if fun is appropriate for this discussion – is a card game called “Go Wish.” It’s like playing solitaire – you take cards with value statements such as “To Be Mentally Aware,” “To Be Free from Anxiety,” “To Say Good-bye to Important People in My Life,” “To Be Free from Pain” and “To Have My Family with Me” and array them under the categories of “Not Important,” “Somewhat Important,” and the top-10 “Very Important.” You can play it on-line at GoWish.org and then print off your array of the cards and talk about them with your family. Or you can play it on-line with someone, talking about your choices together.

I also am a resource in thinking about these issues. I am always happy to meet one-on-one to talk about your wishes. Because it can be helpful to hear what others are thinking, in February or March I’ll be offering a chance to get together to reflect on some of these questions. And I invite you to join me in reading Atul Gawande’s book *Being Mortal* and talking about it after church on a Sunday in January. If there are other ways you’d like to see this conversation raised here at First Parish, please let me know.

And over Thanksgiving, after the turkey and pies are finished, after you’ve discussed the relative merits of Donald Trump and Marco Rubio, Hillary Clinton and Bernie Sanders, and the Patriots’ chance of making Super Bowl 50, I invite you to have “The Conversation.” Make sure that the people you love have the space to say what they need to say. Make sure you have the chance to say what you need to say. Make sure you make known what needs to be known. Make sure that each of you is “freed to say yes to the cosmos.” Offer the ones you love the gift of writing and living the best story possible.

- Pamela M. Barz