

10, November 2014

# HUFFPOST BOOKS

## We Are Not Ready, But We Could Be: On Gawande's 'Being Mortal'

Michael Friedman, L.M.S.W.

Adjunct Associate Professor, Columbia University School of Social Work

About a quarter of the way through Atul Gawande's wonderful, disturbing, but ultimately hopeful new book, *Being Mortal*, I said to my wife "We've got to talk!" I had become convinced that we are not ready for death or, more precisely, for the long period of declining capabilities and pain that Gawande warns us is the increasingly common prelude to death in modern society.

I had thought we were ready. We have wills, health care proxies and durable powers of attorney. We have had the conversation everyone needs to have about when -- if ever -- to pull the plug and what to do with our bodies. We have talked about who to notify and memorial services. We have written a letter for our daughter- - our only child -- telling her where to find all the important papers, who to contact regarding our finances, what our preferences are and that we love her. (We have not talked with her face-to-face about all of this; but she is a grown-up now, so we are planning to do it soon.)

Despite all that, we are not ready.

We are not ready to become almost totally dependent on one another, to be helped out of bed, to be helped to walk, to be helped to eat, to be helped to -- and perhaps in -- the shower, to be helped to -- and perhaps on -- the toilet. We are not ready despite the fact that I have been there already. But we knew it was temporary; I would recover.

Each of us is ready to provide help -- my wife probably more than me -- but neither of us is ready to need help or to accept it graciously. And what if we are both disabled? Call in home health aides and create a mini nursing home in our apartment? I am not ready to live like that. And when one of us is dead? What then? Who will take care of the survivor when that becomes necessary? We do not want to go to a nursing home, and we don't want to burden our daughter. Who, then? And where? Should we move to a life care community now, assuming we could afford it?

We are not ready.

Nor, according to Gawande, are our doctors ready. He -- an obviously thoughtful and caring surgeon -- confesses how clumsy he has been talking with his patients about terminal or permanently disabling diseases or injuries. He tells us that he has not known how to help his patients understand their conditions in a way that does not devastate them and which leaves them able to think about and decide what they should do.

Should they have the operation they "need"? Should they have chemotherapy, radiation or other treatments that will probably be painful and debilitating? Should they fight to live, or should they come to terms with the inevitability of death? Should their doctors encourage them -- or even demand -- that they accept all the treatment that offers any glimmer of hope, or should their doctors at some point accept the inevitable and help them to make the best of the time they have left?

Gawande, as I read him, believes in fighting for life, and he explicitly opposes physician-assisted suicide. But he understands that at some point, it is not possible to have a life worth living. What this point is, he tells us, is a tricky matter. People adapt to their disabilities. People develop new perspectives on life and tolerate, even thrive, in circumstances that are unimaginable when they are fully healthy and independent. Whether life is worth living is subjective. One man Gawande tells us about wants to live as long as he can eat chocolate ice cream and watch football on TV. Another - - Gawande's father -- would prefer death to becoming dependent and unproductive. Choices about risky treatment or treatment to prolong life are different for the two of them.

The core of having a life worth living, according to Gawande, is retaining the capacity to be the "author" of one's life. Obviously, that does not mean having full control. None of us ever has full control, but we can be more or less independent and more or less able to make choices to shape the lives we have.

The doctor's job, Gawande maintains, is to facilitate personal authorship. And this, he tells us, is not something most doctors are prepared to do. Yes, the style now is to give patients information and leave the final choice to them rather than just telling them what to do. But often, the information is overwhelming or shaped towards the doctor's preferences. How can patients sort out the most relevant information without help? What do they need to know so that they can make informed choices as they near the end of their lives?

To help, doctors have to understand who their patients and their families are and what they want from life. And most doctors, Gawande tells us, are just not prepared to do this.

But, he also tells us, they could be. They could come to appreciate that life can be better or worse towards the end. They could come to appreciate that there are ways to facilitate a conversation that informs the decisions that need to be made and that helps people to have as much of the life they want as they can despite their decline into disability and their drift towards death.

There is a conversation that our doctors need to have with us and that we need to have with the people who will be with us at the end. This is a conversation that we will need to have again when disability and death become not just an abstract truth, but an imminent reality. This is a conversation that will give us hope, not of immortality, but of having the death we desire.

Gawande's is a grim view of mortality in a world in which people live longer and better in part because of advances in medical treatment. What makes life better also makes its end less likely to be what most of us want it to be -- death at home surrounded by those we love and those who love us.

But, remarkably, Gawande's view is also hopeful. He believes that medical practice with people who are dying can be better. And, he believes that despite the shrinking boundaries of our capabilities, we can retain authorship of our lives far into the process of dying -- if we, our families, and our health care providers are ready.