



## ON BEING MORTAL

I recently read Dr. Atul Gawande's book "*Being Mortal*" and I highly recommend it. You may have seen him on the book promotion circuit on Frontline, morning talk shows or on the Daily Show, or perhaps you have watched his TED talk. He is a surgeon at Brigham and Women's Hospital in Boston and a professor at Harvard Medical School as well as a well-regarded writer. Through research and stories, Gawande describes how we—both people and medical professionals—avoid dealing with death, resulting in high costs and great discomfort. Reading the book prompted me to commit to doing more at PSRC to engage in conversations about quality of life and death.

Gawande reviews the relatively rapid changes in how we handle aging and death in the U.S. As recently as 1945 most deaths were quick, precipitous and occurred at home, but by the 1980's, 83% were dying in hospitals. U.S. life expectancy in 1900 was under age 50; today it is past 80. Thirty years from now there will be as many people over 80 as will be under age 5. There aren't enough people choosing geriatric medicine to treat this growing population. Gawande points out that in 1900, 60% of those over age 65 lived with family and by 1975 that number had dropped to fewer than 15%. A quarter of Medicare spending is on the 5% of patients who are in the last year of life; most of that spending is for the last couple months and are of little apparent benefit.

Societies respond slowly to such rapid change. Gawande describes the often-unintentional evolution of elder care from the 19th Century, when people went to poor houses when they did not have family caregivers and their funds ran out. Care moved from home to hospital to nursing home to assisted care, continuing care and Eden Alternatives, and back home with homecare and Village networks. Now, much care is provided by families once again. It has been exciting and challenging for me to observe these evolving transitions and develop PSRC's role as a resource center to help people make the right choices for them.

I think we are on the brink of the next sea-change. Gawande is determined to change the way we manage end of life care. He describes what he learned from geriatricians, hospice workers, and his patients about the critical need for patients and doctors to be able to talk about the end of life and to shift the focus. "We've been wrong about what our job is in medicine. We

think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.”

Gawande quotes one geriatrician: “The job of the doctor is to support quality of life: as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world.” As a culture, we value independence above all else. Gawande argues that what older adults really want is autonomy, the ability to make decisions, often choosing autonomy with some risk over safety. We seek purpose and worth throughout the lifespan. We want to avoid being so diminished that “who we are becomes disconnected from who we were or who we want to be.” Hospice workers focus on helping a person have the fullest possible life right now. Surveys of critically ill people indicate their top concerns include not suffering, not being a burden on others and achieving a sense that their life is complete.

“Endings are not controllable...No one ever really has control, but we are not helpless...courage is the strength to recognize both realities. The sick and aged have priorities beyond being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives (p 243).”

It excites me to think about PSRC’s role in this change. I believe PSRC can help Princeton move toward what La Crosse, Wisconsin, achieved in the 1990s: more than 85% of residents who died had written advance directives. All patients admitted to the hospital wrote one. One doctor noted that this has made his job easier, not because the specifics are written, (they change over time and with changing circumstances), but because people have had conversations that helped them accept their mortality, navigate their anxiety, and identify what their definition of “quality of life” is. Professionals need to sit down and listen carefully and then provide information and guidance. Gawande shares the questions a palliative care specialist taught him: What do you understand your prognosis to be; what are your concerns about what lies ahead; what kind of trade-offs are you willing to make; how do you want to spend your time if your health worsens; who do you want to make decisions if you can’t? He reports studies that indicate that people who had discussions with their doctors were more likely to die at peace and in control of their situation and to spare their family anguish. Those who chose palliative care actually lived 25% longer!

PSRC’s professional staff will listen to you if you want help working through these questions so you can begin the conversation with your family and doctor(s). We will help you complete an advanced directive. And this month we will start a new discussion group: Conversations on Being Mortal. We will discuss the concepts raised in the book, explore what quality of life means to each of us, and work on conquering our discomfort with talking about death and dying, and we’ll follow where that takes us. Please join us on Monday, March 23 at 2:00 p.m.

Susan W. Hoskins, LCSW