

The Passy Press

Letter to the Editor

From: roodad@undisclosed.com

To: Nick Gardiner enpg@thepassypress.com

Date: December 30, 2014 4:21 p.m. EST

Subject: Essay on Death With Dignity by Charles Hamlin, MD

Dear Sir,

Dr. Hamlin's essay had a special meaning for me and prompts me to expand the commentary on a personal level.

On the Sunday before Thanksgiving I lost my Mom. Obviously, I didn't just misplace her, despite the fact that there were multiple periods of "Where's Waldo?" episodes as she bounced between various sites and levels of care throughout the greater Boston area. So no, we didn't lose track of her, but she died after a long and accelerating slide into the encyclopedia of symptoms that can come with being 93 years old. Finally, following an episode in which she broke her (second) hip, she simply stopped railing against the world and accepted a quiet and relatively comfortable end. It was a blessing to have her free from a level of pain that was becoming ever more constant.

It was also an outcome that should not have been, nor was it, unexpected but I am still surprised by how the finality of it has hit me. No one has, nor should have, much sympathy for a 60 year-old orphan, though that is exactly what I've become.

My Mom's last few years have forced me to open my eyes to the reality of health care and life care for the elderly in the US. It is not a sight for the squeamish. Both my brother Pete and I have deep experience in the health care system, but we have been repeatedly surprised by the illogic, disconnects, and end to end inefficiency. Even granting that Mom could fairly be described as being at the difficult end of the patient spectrum, her journey was a frightening preview of what's ahead for many of us. While any discussion of health care can too easily get lost in complexity and politics, there are two core themes that emerge for me.

As we dealt with what increasing became clear was the end game for Mom, I picked up Atul Gawande's new book *Being Mortal*. For those who don't know his work, Gawande is one of those guys who seems to be able to do anything well – he is a surgeon at Boston's Brigham and Women's Hospital, a health writer for *The New Yorker*, a MacArthur Fellowship winner, etc., etc. He writes as clearly and intelligently about health as anyone today, even when clarity and intelligence appear to be lacking in whatever aspect of the system he is examining at the time. *Being Mortal* tackles the question of how we have gotten end of life care so wrong and begins to look at what we might do about it. For me it comes down to two fundamental observations: 1) we have become increasingly skillful at extending life while losing perspective on what constitutes quality of life and 2) as a result, we as family members and ultimately as

patients ourselves need to think deeply about what is important to us and our loved ones to make our own choices rather than default to what the system has been built to deliver.

The first observation could be viewed as obvious, but Gawande delves into the different ways that this bias has led to longer but emptier lives. For example, despite the increasing percentage of the population above the age of 65 in all Western societies, the number of trained geriatricians entering practice is actually declining (e.g., by 25% in the US between 1996 and 2010). At some level, this is not surprising. Doctors enter clinical practice to *cure* people. As a general rule, most of the elderly can't be cured, only managed to a frequently unruly end. For another, our general approach to extending life in the elderly consists of institutionalizing them in "safe" settings that increasingly strip them of choice, variety, human interaction and dignity. In other words, systematically removing all those things that make life worth living. We had the opportunity to see this in action as my fiercely independent Mom experienced the acute care to skilled nursing facility to nursing home cycle repeatedly. Each acute episode (real or imagined) resulted in a flurry of miraculous, expensive and high tech care administered to treat symptoms with little hope of long-term benefit, followed by turfing her to the next level of care as demanded by reimbursement policies. Our dark description of this process as we watched it play out was "rinse and repeat."

The best response to managing this bias to treat with diminishing returns and declining quality of life is to make our own choices based on the facts of our situation, filtered through their individual beliefs, values and preferences. Simplifying Gawande's rich set of stories and examples, this comes down to four key questions to be asked not once, but repeatedly. Why repeatedly? Because aging, made visible as a graph, is generally not the long downward sloping parabola we imagine but more typically a series of relatively flat plateaus connected by precipitous declines. Those declines can be the result of accidents (particularly falls in the elderly), various forms of disease, etc. So as we experience each decline, there are four questions to guide our choices:

1. What is your understanding of the situation and its potential outcomes?
2. What are your fears and hopes?
3. What are the trade-offs you are willing to make and not willing to make?
4. What is the best course of action that best serves this understanding?

These are tough questions to ask, particularly in the immediacy of a health crisis and ones that we should not expect most physicians to ask us. Nor can we always depend on the patient (even when that patient is us) to ask them. We may need to be the person that has the hard conversation with the people we love when choices are necessary. I can't do justice to the case studies that Gawande provides, but the benefits of making the right choices in difficult situations guided by those four questions becomes very clear. I can't recommend the book highly enough for those of us who are, uh, of a certain age.

Sincerely,

David Mahoney

David Mahoney is a graduate of Princeton University and Harvard Business School. He lives in San Francisco and is a private equity investor and board member across various industries and institutions. He is currently a board member of Corcept Therapeutics, Symantec, Schwab/Laudus Funds and Adamas Pharmaceuticals. His non-profit work includes board service at SFMOMA and Mercy Corps and he previously served as co-CEO at McKesson HBOC and as a Principal at McKinsey & Company.