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## Book Review: *Being Mortal: Illness, Medicine and What Matters in the End*

Written by Atul Gawande, MD

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Atul, Gawande, MD. (2014) In *Being Mortal: Medicine and What Matters in the End*. USA: Metropolitan Books.

Dr. Gawande, a bestselling author, practicing surgeon and researcher, follows geriatricians and hospice nurses, and interviews patients about what it is that matters most to us as we face the inevitable end of our lives. Through his research, storytelling and experience with his own family, he finds people who show us how to have the hard conversations with patients and families to assure that the goal is not a peaceful death but living a good life to the end with autonomy, dignity and joy.

*“We have come to medicalize aging, frailty, and death, treating them as if they were just one more clinical problem to overcome. However, it is not only medicine that is needed in one’s declining years but life – a life with meaning, a life as rich and full as possible under the circumstances... Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.”*

He tells stories about patients who spend their last precious days in the hospital with treatments that will not extend their lives. Nursing home patients who are “feisty” and resisting structure as being restrained in beds and wheelchairs or otherwise tamed. Patients are forced to share rooms, given inflexible diets, and times to eat/sleep are all structured around the “business” of taking care of patients not the individual. In his research he finds that most elderly patients would like to remain in their own homes with family and friends and don’t want to trade their health for freedom and a life worth living. The answer is not more social activity as some suggest, but fewer and more established friends as everyday pleasures and relationships reduce the anxiety and depression of facing declining health. This leads towards caring for patients in their homes, assisted living or hospice.

In this day of increased focus on understanding patient’s expectations and patient-focused care, Dr. Gawande compels us to learn how to have the difficult conversations about what really matters and what each person wants during their declining years. Not to focus only on disease and institution, but also to understand how

to attend to individual’s preferences bringing grace to this inevitable part of the continuum of life.

During his research he speaks with Susan Block, a palliative care specialist, to help him identify best practices in managing end-of-life discussions with patients and their families. Block stated: *“You have to understand... A family meeting is a procedure, and it requires no less skill than performing an operation”*. Block goes on to say that a large part of the task is helping people negotiate the overwhelming anxiety about death, suffering, loved ones, and finances. She believes patients must arrive at a point of acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine.

She and Dr. Gawande discuss the best way to have end-of-life discussions to help determine what decisions need to be made to support the wishes of the patient and family. Susan shares what she has found to be the best process for these discussions.

### Rules for End of Life Discussion

Sit down with the patient and family. Make time to do as much listening as talking. Ask the following questions after stating, *“I wish things were different.”*

1. *If time becomes short what is most important to you?*
2. *What do you understand the patient’s prognosis to be?*
3. *What are your concerns about what lies ahead?*
4. *What kind of trade-offs are you willing to make?*
5. *How do you want to spend your time if the patient’s health worsens?*
6. *Who do you want to make decisions if you can’t?*

Dr. Gawande believes that we need to change our relationship with patients. The oldest kind is a **paternalistic** relationship— we are medical authorities *“priestly, doctor-knows-best model”*. The second type of relationship is **“informative.”** We tell you the facts and figures. The rest is up to you. A third type is **“interpretive”**. Here the doctor’s role is to help patients determine what they want through a shared decision-making model. Interpretive doctors ask, *“What is most important to you? What are your worries?”* In this shared decision-making model physicians and patients can come

to agreement on the treatment plan that would best meet the patient's own priorities. In moving towards this model and using the skills honed by palliative care experts, Dr. Gawande believes we can provide a more humanistic approach to dealing with inevitability of mortality.

In the epilogue Dr. Gawande states:

*"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... If to be human is to be limited, then the role of caring professions and institutions ought to be aiding people in their struggle with those limits. I never expected that among the most meaningful experiences I'd have as a doctor— and, really, as a human being— would come from helping others deal with what medicine cannot do as well as what it can."*