Atul Gawande, *Being Mortal: Medicine and What Matters in the End*, Metropolitan Books, 2014, $15.60 (Hbk), ISBN 9780805095159

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Modern medical advances have lengthened the human life span, such that it is now longer than it has been at any point in human history. These advances happened alongside the process of industrialization and urbanization, leaving a growing aged population without the family and social structures which provided care in more traditional agrarian communities. It was in this context that the modern nursing home developed and, with the practice of medicine emboldened by its ability to stave off death, that a particularly modern approach at the end of life developed. As Atul Gawande notes in his book *Being Mortal*, ageing and death have become medical experiences in a way that is unprecedented – and the results have not been unambiguously good.[1] Gawande, a general surgeon at Harvard, draws on a mixture of vignettes, scholarship, and personal reflection to explore the history and reality of our current predicament, and to examine alternatives that have sprung up in response, searching for insights into how the situation might be improved.

While Gawande's book is meant to be a broader reflection on human mortality, its greatest contributions come in the form of reflections on assisted living for the elderly and on care at the end of life. Early in the book he shares the story of his grandfather, who lived to be 110 in rural India. His grandfather's 'independence' was sustained until the very end, enabled by the support of family and friends. This support was expected in cultures where a reverence for elders was paramount. He died after a fall on his way out of a taxi, and his decline was precipitous. Such social

1 Gawande, Atul. Being Mortal: Medicine and What Matters in the End. New York: Metropolitan, 2014. Print.

support, and rapid death after illness or injury was typical until the advent of penicillin and sulfas - and eventually dialysis, chemotherapy, advanced surgical techniques, and life support – which have allowed medical teams to see their patients through previously fatal conditions.

The transition to modern post-industrial capitalist social structures initiated a move away from the agrarian way of life, brought with it the dispersal of families, and led women (traditionally responsible for most of the caring responsibilities) into the workplace. The structures of family and community that had long been the source of support for the elderly were weakened, necessitating the outsourcing of care to 'assisted living' facilities, all with a growing aged population. In addition, the process of dying changed dramatically. Where death was once precipitous, today it is more often protracted. The systems of care that arose in response to these realities emerged more out of necessity than design, and the medicalized approach that they typified often failed to account for the humanity of the person entrusted to their care.

Nursing homes were originally designed as transitional places between hospitalization and the return home. They were conceived as medical institutions for rehabilitation and treatment. Today, however, they have become destinations – homes – for those who can no longer live independently. Gawande echoes Erving Goffman, who in *Asylums* noted the similarity between nursing homes and penal institutions. In contrast to normal life, he observes, nursing home life is highly structured, similar to life in a prison. It consists of scheduled group activities, all of which take place in one broader confined space, with little privacy and minimal opportunity for self-determination. In these respects both prisons and nursing homes are inorganic and inhuman. Nevertheless, as Gawande notes, a number of alternative care models have developed. The 'assisted living' movement, which seeks to provide spaces of care with privacy and maximized self-determination have grown considerably in recent years. Gawande also shares stories of experiments elsewhere: of introducing dogs, cats, birds, and gardens, and of attaching childcare facilities to infuse life and normalcy into an otherwise sterile environment. Bill Thomas, a pioneer in this movement identifies the nursing home's three plagues: boredom, loneliness, and helplessness. His response? Provide independence, company, and living things to tend to.

A central insight of Gawande's narratives is that nursing homes, as medical entities, are safety-obsessed. In such an environment people are reduced to patients, and care is reduced to treatment. Nursing homes mistake safety for an end rather than a means. Instead of a home, the elderly are

afforded an institution. This is partly because safety and medical 'outcomes' are measurable, which enables the government to hold these institutions accountable and the institutions themselves to set goals. The whole system is thus geared to ensure safety, whatever the cost. While still prioritizing safety, alternative models have tended to refocus on a broader concept of care, enabling self-determination, promoting community, and creating a home. In these contexts, safety and medical compliance are means to enable the flourishing of the person, considered alongside the many other goods that human beings need in order to flourish.

After addressing elder care, Gawande reflects on care at the end of life. He notes that medical technology has given physicians a remarkable ability to sustain life even as organs are failing. Dialysis, ventilators, pacemakers, and LVADs all assist or take on the role of tired organs. These technologies and the confidence that comes with having them at one's disposal have contributed to a culture in medicine that often favors doing 'everything' for a patient, frequently by default. This is epitomized in the Intensive Care Unit, where the common question 'What are we doing here?' lingers in the background. As Gawande notes, there is rarely 'nothing more' that doctors can do, and the prominence of a default vitalism has left patients as well as doctors dissatisfied. But how did we get here? As Gawande observes, it was in many ways accidental; advanced medical science presented physicians and families with new questions for which centuries of tradition and experience did not have the answers.

Medical culture is, in great part, oriented towards sacrificing the now in order to enable better health in the future – surgery and chemotherapy for example (and many other treatments) do definite harm in pursuit of a foreseeable good. This orientation is appropriate when removing a 15-year-old's appendix, or treating a curable leukemia, but can be less appropriate in terminal cases when time is short and costs often outweigh benefits. As Gawande says, 'Our interventions and the risks and sacrifices they entail are justified only if they serve the larger aim of a person's life'.[2]

This contrasts with hospice care, which focuses on the immediate – intentionally stepping back and acknowledging the person and what is important to him or her, recognizing physiological function as a means rather than an end. Gawande spends a good deal of time reflecting on the reality of human mortality, emphasizing that those who recognize it and have conversations with loved ones

2 Ibid.

about their priorities at the end of life will be less likely to be swept up into a potentially vitalistic system – one that sees prolonged life as the only good – and will instead allow them to die as much on their own terms as their particular situation permits. This approach is beneficial for the individual and has been shown to reduce the anguish of loved ones left behind. The necessary conversations are difficult, but communicating priorities and drawing lines in the sand (Do Not Resuscitate orders, etc.) are important.

One vignette Gawande draws on recounts a woman in conversation with her father. Her father informs her that he will be content as long as he can watch football and eat ice cream. During an operation on her father's spine, the surgeon encounters some difficulty and seeks the daughter's input about whether to proceed. The daughter recounts her father's wishes and, framing the goals of the surgery in those terms, provides the surgeon with the information he needs to resolve to proceed. Making medical decisions requires identifying one's priorities and calling them to mind in the foreign environment of the hospital, in order that they might guide care.

The most difficult part of hospice care is perhaps the requisite recognition that death is impending, and a philosophy of care that steers away from the hospital. Mortality is, of course, inescapable, but hospice insists its inevitability be acknowledged – something, Gawande notes, that many are ill-equipped to accept. The same pertains to the loss of independence and transition to assisted living. This lack of preparedness stems in part from what Gawande refers to as the 'veneration of the independent self'. Here he gestures at what might be a fuller account of the problem, though one which he does not stick to throughout: Later, Gawande states 'all we ask is to be allowed to remain the writers of our own story'; but of course for many this will be an illusory goal.[3]

There is a notable contrast between those for whom the transition to assisted care and hospice care is unbearable and those who do so with grace (and by this I do not mean 'with resignation'). It seems to me that Gawande exhibits a blind spot here, induced perhaps by an unwillingness to critique his father, whose own end-of-life narrative features prominently in the book. Gawande's father, an accomplished and fiercely independent man, is shattered by his progressive loss of independence due to an enlarging spinal tumor, and his ensuing dependence on his family leaves him deeply unhappy.

3 Ibid.

Struggling with new-found dependence is not an uncommon experience, but as Alasdair MacIntryre points out in *Dependent Rational Animals*, dependence is a fundamental characteristic of our human condition – at the beginning of life, throughout childhood, during periods of sickness, and later in life, we are invariably reliant on others. In the *Nicomachean Ethics,* on the other hand, Aristotle's Magnanimous Man is 'proud to remember what he has given and ashamed of what he has received' an ideal echoed by Adam Smith. Gawande's father appears to be characterized by this disposition and is left frustrated and ashamed as his independence deteriorates. MacIntyre notes that once we acknowledge our animality and inherent dependence on others, we realize that this will require a set of virtues, which MacIntyre calls the 'virtues of acknowledged dependence'. For the one cared for, these virtues lead to 'knowing how to exhibit gratitude, without allowing that gratitude to be a burden' ; such virtues 'are bound to be lacking in those whose forgetfulness of their dependence is expressed in an unwillingness to remember benefits conferred by others.'[4] The illusion of self-sufficiency leads to frustration and furthermore undermines the one cared for's relationship with the caregiver.

The caregiver's corresponding virtue is *misericordia*, an attentive and affectionate regard for the other and his or her distress. Compassion is a dimension of misericordia; and it is something Gawande never quite puts his finger on, though he points to examples of it in the actions of physicians, nurses, and others throughout the book. The ideal he points to, instead, is Gerasim, who cares for Ivan Ilyich in Tolstoy's *The Death of Ivan Ilyich*. Gerasim cared 'easily, willingly, simply, and with good nature that touched Ivan Ilyich'.[5] He was a companion, an assistant, and sought to help Ilyich achieve his modest aims as he neared the end of life. He displayed a compassion that both moved and soothed the hardened Ilyich in a way that enabled him to acknowledge his dependence and to be at peace with receiving care.

What becomes clear in reading Gawande's book is that individual and family preparation will require conversations to make the end of life more readily navigable and less agonizing for loved ones. Furthermore, it is essential that nursing homes be reoriented towards a broader concept of care and human flourishing, beyond the purely medical or physiological. In this context,

4 MacIntyre, Alasdair C. Dependent Rational Animals: Why Human Beings Need the Virtues. Chicago, IL: Open Court, 1999. Print.

5 Tolstoy, Leo, and Aylmer Maude. The Death of Ivan Ilych and Other Stories. New York: Signet Classic, 2012. Print.

compassion in the caregiver is vital – to seek to know the people under one's care, to learn about their past and their priorities, and to enter into their suffering with them. This type of care is challenging. It requires time and patience, but it is also human rather than mechanistic. Such caregivers ask the questions Gawande revisits. Who are you? What is important to you? What are you afraid of? Asking these questions is a practical step towards transforming shortsighted, strictly physical treatment into more holistic care and enabling the caregiver to be a companion. This transforms and humanizes the relationship, and promotes the well-being of the caregiver and the one cared for.