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Death and Dying in the Age of Autonomy

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

"For a clinician . . . nothing is more threatening to who you think you are than a patient with a problem you cannot solve" (8). Surgeon Atul Gawande places himself before *the* insoluble problem in *Being Mortal: Medicine and What Matters in the End*, an examination of aging and death and their transformation in the twentieth century. Adeptly weaving memoir and broad field research, Gawande explores the limits of his profession and the wider culture in the face of death and dying. The work unfolds in eight chapters whose progression conveys the paradox and the drama of aging in terms of the importance, and limits, of autonomy: "The Independent Self," "Things Fall Apart," "Dependence," "Assistance," "A Better Life," "Letting Go," "Hard Conversations," and "Courage." Chapter by chapter, Gawande chronicles his own growth as a physician and a man as he probes the inescapable end of every person from the double vantage point of a medical ethos that views death as failure and a culture that prefers not to think about it at all.

Aging and death, after all, call the independent self into question. Reviewing twentieth-century demographics, Gawande shows that this notion has never been so entrenched as it is today. As life expectancy increased in the United States, family sizes decreased, and what was formerly a demographic pyramid, with a large base of young children and a small peak of elderly people, is undergoing a "rectangularization" as medical care improves. Now 50-year-olds and five-year-olds are present in the same numbers, and in a little over a generation the over-80 set will likely roughly equal those under five. Tellingly, the residential distribution of this population has shifted significantly. In early twentieth-century America, 60% of those over 65 lived with a child; by 1975, that number was just 15%. Similar trends can be seen in Europe and even in Asia, where permitting the elderly to live alone has traditionally been regarded as a dereliction of duty. In 1945, most deaths in the U.S. happened at home; by the 1980s, only 17% did.

The son of immigrants from India, Gawande illustrates this cultural shift by way of examples from his own family, contrasting the last years of his wife's grandmother, Alice Hobson, who died in her mid-eighties on the skilled nursing floor of a high-rise senior living facility in suburban Virginia, with those of his own grandfather, Sitaram Gawande, a farmer in the village of Uti, three hundred miles from Mumbai. Sitaram, who lived with a son and his family, died at the age of 110 on his way to the courthouse to conduct some business. Although in the United States he, too, would likely have been confined to a nursing home at the end, Sitaram, embedded as he was in a wide network of lively family relations, maintained his habit of inspecting his fields every evening until he died. To be sure, Alice maintained a remarkably active life also, until two years before her death. But since she lived alone in her home, Alice had no immediate buffer to absorb the vagaries of a slowly failing body and mind. All her children could do was send her to the doctor and help her take the dramatic step—culturally normalized but nonetheless wrenching—of finding a new residence at the age of eighty-four. But a new residence is not the same as a new home, as Alice wistfully observed in her assisted living apartment.

Gawande takes stock of the disparity in the modern American and traditional Indian experiences of aging and death, noting, "Modernization did not demote the elderly. It demoted the family. It gave people—the young and the old—a way of life with more liberty and control, including the liberty to be less beholden to other generations" (22). In some respects, Gawande finds this praiseworthy. "There is arguably no better time in history to be old" (20), he says, when this means that an aging person can maintain his health so as to conduct his life as he sees fit, from his own home, for as long as possible. But medical advances and modern social mores aside, the human body does not support independent living forever. At the end of life as at the beginning, the body testifies poignantly to the perduring social nature of human beings, even if the strength of our middle years can cause us to forget it. We depend on help, ever more so as our strength and stability wane. And since a variety of socioeconomic factors make families less able or less disposed to be primary caregivers of aging relatives, other institutions have been drawn into the vacuum.

Gawande chronicles the advent of the modern nursing home, which developed at mid-century "more or less by accident" as social policy planners confronted the problem of poorhouses, filled persistently with frail, aging persons. During precisely this period hospitals were being built in unheard of numbers across the country, and medical breakthroughs changed their character dramatically: from places where the sick would be well-tended to places where the sick could reasonably expect to be cured. Social welfare agencies thought hospitals might be a good refuge for the aging and infirm poor as the poorhouses closed. But the infirmities of age were not something medicine could cure. Hospitals petitioned the government for relief, funds were granted, and separate nursing facilities were conceived. Not, however, conceived so much to facilitate the flourishing of these patients in their remaining years as to ease pressure on social institutions. "This place," as Gawande says, "where half of us will typically spend a year or more of our lives was never truly made for us" (72).

The challenges of gathering a large number of frail persons of failing strength and health under one roof are immense and complex, to be sure. For a comparatively small staff to meet the basic requirements for the survival of a complicated and highly dependent group, a certain efficiency seems necessary. And the path to institutional efficiency often involves the sacrifice of the predilections, idiosyncrasies, intimacies, freedoms, and responsibilities that permit a patient to recognize his life as his own. In Gawande's language, it is privacy and autonomy that easily fall by the wayside in a nursing home environment, because of the sheer time it takes to respect the different habits, preferences, and desires of particular persons. To create a manageable situation, differences among persons seem to have to be repressed. It takes time,

after all, to dress or feed a person in the manner he likes—and even more time to make it possible for him to do the dressing or feeding himself. Hence the reluctance of the elderly to land in a facility where too often this time can't or won't be spared. The sacrifice is countenanced by family members, even if they too are reluctant, because it seems to be the condition of securing the safety of their loved one. Gawande quotes a colleague of one of his interviewees: "'We want autonomy for ourselves and safety for those we love'" (106).

Some remarkable creativity has been deployed to bridge that disjunction at the institutional level. One of the most enjoyable and revealing features of *Being Mortal* is the series of interviews with a variety of reformers of the nursing home model, with which Gawande contextualizes his stories of particular elderly men and women seeking, and sometimes finding, an adequate home. Home is important because it is a place and an order in which a person can make decisions and bear responsibilities—in other words, can be himself. Gawande speaks with the founder of the first assisted living residence, which opened in Portland, Oregon, in the early 1980s. Here there were no "patients," only "tenants," and although the support services available were essentially the same as nursing homes provide, institutional regimentation and homogenization were avoided as staff retained the awareness that they were entering someone else's order, someone else's home. Greater freedom means greater risks, but tracking the health and satisfaction of the residents of the first facility revealed that physical and mental health was maintained or improved and satisfaction increased.

In one of the book's few comic vignettes, Gawande also gets to know a doctor charged with the administration of a nursing home, who performed a different kind of institutional reform. Upon noticing the widespread depression at the facility, he addressed the problem—against the incredulous objections of other staff and the clear dictates of housing code—by introducing plants, dogs, cats, and a hundred birds into the premises. Where there is no life, put life, and you will find life. The effect on the residents was transformative as survival shifted to observation, engagement, and responsibility for these living, growing arrivals. Gawande frames this story effectively with a discussion of Josiah Royce's "philosophy of loyalty," the idea that central to human happiness is finding meaning outside of oneself.

As the subtitle signals, *Being Mortal* is not only about the human condition, as it plays out between the poles of dependence and independence in families and in the warp and woof of the social fabric, but also about the medical profession. An unwelcome role reversal in the final chapters of the book draws Gawande into deeper insights about a particular kind of interdependence: the doctor-patient relation he had been practicing for years. He and his parents, three doctors accustomed to problem-solving from a certain affective distance, find themselves suddenly, uncertainly facing his father's slow-growing but ultimately fatal spinal cord tumor as a patient and next-of-kin. Now encountering the medical establishment on the receiving end, Gawande recalls an ethics paper assigned in medical school that defined two common but fragmented ways physicians exercise their authority: on the one hand, the "paternalistic model" in which the doctor makes all the decisions based on his expertise with minimal explanation to the patient and, on the other, the "informative model," in which the physician makes himself merely a conduit of knowledge about treatment options and foreseeable consequences but leaves decision-making entirely in the patient's hands. In his medical experience in the meantime, Gawande has come to recognize these two lopsided types as prevalent and sees tendencies toward "Dr. Informative" in his own habitual approach to patients. But in seeking care for his father, he meets a physician who represents the comparatively rare third type: the integrated "interpretive model" in which the physician listens to patients and offers guidance, on the basis both of his expertise and of their personal situation and priorities. Although Gawande sometimes tends in the direction of simply making

patient autonomy the measure of end-of-life care, he presents a more complex relational task here. The interpretive physician, in attending to his patients' desires, is not simply putting his skills at their service. "At some point," he writes, "it becomes not only right but also necessary for a doctor to deliberate with people on their larger goals, to even challenge them to rethink ill-considered priorities and beliefs."

Without naming it, Gawande affords us a glimpse of the virtue of prudence in the example of the interpretive physician, a healing balm for a fragmented medical establishment. In accord with classical ethics, only the one faced with a decision—in this case, the patient—has the capacity and authority to render a prudential judgment about how to proceed, but he can be *helped* in this by another prudent man, a friend who will take his part without losing sight of the good—in this case, his doctor. Patient autonomy and physician's authority both take on a new cast here, as they meet in mutual subordination to something deeper than wishes and information. No small measure of courage is required of the aging person, his physicians, and his family members, if they are to face their circumstances in this way. Gawande offers numerous accounts of situations in which physicians, himself included, take the easy way out in communications with patients nearing death and watch unsatisfying consequences ensue. But in following the work of a hospice nurse, he learns the value of facing the realities of finitude together through hard conversations and some practical ways of actually conducting these, both as a physician and as a family member.

In *Being Mortal* Gawande has woven a rich tapestry, complex and coherent, portraying a range of paradoxes and polarities that profoundly shape human life, coming to particular expression at its close. As dramas of dependence and initiative, safety and freedom, survival and meaning play themselves out in persons, families, and institutions, we see how deeply social the human person is, how reliant he is on what is beyond himself for his sense of identity as well as for his simple sustenance. The most serious weakness of the book is that Gawande couches his perceptive depiction of interdependence in terms of autonomy and privacy, borrowing Ronald Dworkin's idea that "autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent that such a scheme of rights can make this possible, what he has made himself." Gawande's misapprehension of autonomy tends to obscure the possibility that it could be good, truly human, to be led—that, as important as freedom and responsibility are, self-abandonment need not be self-alienation. This mistake leaves him open to, though not enthusiastic about, assisted suicide. It is left to other writers to show that the tension between autonomy and the ultimate "letting go" finds its final resolution in the *dialogical* character of our ineluctable death, expressed in the words the Church gives us to pray each night: "Into your hands, Lord, I commend my spirit" (Lk 23:46). "Now you let your servant go in peace, your word has been fulfilled" (Lk 2:29).

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