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*“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.”*

*–Atul Gawande*

Last week, I flew home to Atlanta to see my parents but for a reason I’ve avoided for many years: *end-of-life planning*.

Five years ago, my mother approached me to discuss her plan to prepare a living will in the event of her or my father’s death. In a moment of personal weakness, I refused to have the conversation and abruptly left the room. I’ve long been deeply uneasy with the thought of my parents passing despite having witnessed numerous deaths of friends, partners, and members of my extended

family. As I moved to Los Angeles to Philadelphia and most recently to Austin, I've remained afraid of getting that dreaded phone call in the middle of the night. The deep fear of being helpless hundreds of miles away, of not being able to help in an emergency, or even worse, missing the call entirely and not even knowing disaster had struck. With my father having recently turned 74 and my mother 66, I feel not only my own aging but also theirs. *The call will come no matter how much magical thinking I project.*

I recognize the great disrespect I showed my mother in that moment of selfish refusal. As my partner and so many of my friends have reminded me, my mother came to me in spite of her own anxieties about her mortality to help prepare *me* for the inevitable. For those that know my mother, she is a remarkable pragmatist and planner—the kind of woman who has imagined and foreseen every possible scenario so that she is never caught off-guard. Navigating corporate America as a 5'2" immigrant woman of color with a limited education meant playing defensively and acting decisively. “*You act before the time of crisis; reacting is already too late,*” she frequently tells me in our Chinglish banter. The end of her life is no different: it is, like all other aspects of her own life, reducible to a series of steps, of decisions made in advance and executed as planned. As much as I've struggled to emulate her crystalline approach to past, present, and future, I've envied my mother's conviction and clarity—so often able to act without the doubt and anxiety that so often keeps me from doing what needs to be done. In my mother's framework, planning ahead dispels this anxiety by making palpable the seemingly unknowable qualities of the future. For me, I reside in the dread of the unknowable that sometimes becomes inevitable. The feeling of seeing what I knew would happen transpire. (Self-fulfilling prophecies, mostly.)

I tried to channel my mother's approach in my own preparations before boarding the plane home. In true academic fashion, I researched and cobbled together checklists and documents that did precisely what my mother would do: reduce a complex problem into identifiable steps and procedures. *Would you like to be intubated? List all of your liquid assets. Designate people who you would trust with your medical care and decision-making.* As much as I found the whole process of transforming death into various forms of legalese and signed papers distasteful, it made the conversation palatable by reducing the enormity of “end of life.” We could make small decisions together, one at a time.

*Then, a call did come.*

My grandmother, who turns 99 this year, had fallen in the bathroom and was unable to call for help. Until she was found by my uncles who live with her, she had been in and out of consciousness. While she seemed to recover over time, she suddenly lost the ability to speak and the ability to walk. After being rushed into intensive care, my grandmother underwent tests that revealed she had a cerebral hemorrhage from her fall now almost two weeks ago. Frantic calls from my uncles and cousins kept returning to a central issue: my grandmother never prepared any advance directives for situations like this one where she would be unable to make decisions for herself or even express her wishes in writing or speech. The irony, of course, is that my grandmother took the time to sort out her financial business, but neglected to consider healthcare and end-of-life care.

Whether she believed she would never be incapacitated to such a degree or that her wishes would be “obvious” to her family, it now fell upon her children and grandchildren to do the guesswork—the risky interpretation of what a woman who has survived both war and domestic abuse might want in the end.

Part of my attempt of reconciling myself to the inevitability of these questions has also been to work through them in my teaching. This fall semester, I have the unusual opportunity of teaching an honors seminar for undergraduates in the College of Natural Sciences. As an introduction to medical humanities and disability studies, my course is a survey of life-writing, poetry, essays, and theory that get at the issue of narrative, which has now become increasingly central in medical education, particularly through narrative medicine forwarded by scholars like Rita Charon who see it as a form of medical practice itself. I decided to dedicate an entire week to aging, death, and dying, which in truth, I had never quite had the courage to teach in previous courses. But if pedagogy is an act of reckoning, witnessing, and transformation, I needed to put that belief into practice, to do the work for my own sake. I envision the unit to be a means of collectively working through the affective intensities that surround the issue of death that we seldom grapple with until we are faced with it.

In the process of choosing readings for that week, I returned to a book that I worked with in graduate school: Atul Gawande’s *Being Mortal: Medicine and What Matters in the End* (2014). Despite my own struggle with talking about death at the time, I collaborated with Perelman School of Medicine’s literature and arts journal, *Stylus*, to host a discussion of Gawande’s book for medical students and clinicians. As I flipped through my dogeared volume, a copy of my discussion questions from that event fell out. Revisiting these questions now reveal just how much I was trying to grapple with my own insecurities around mortality, particularly my own as someone living with chronic illness and disability. I was asking the crowd questions that I was asking myself, that I lacked answers for because the very act of contemplating them felt so unbearable.

To put it simply, *I’m afraid of dying and afraid of the few people who I’ve become close to dying*. Even putting this in writing feels embarrassing—verging on the sentimental, the saccharine, or the pathetic. But as I’ve come to discover, many people I know share these feelings and the same shame that comes with admitting that you are afraid of life’s end.

Gawande’s hybrid form of memoir, case study, graphic medicine, and educational manifesto spoke to me because it contextualized these feelings in terms of the larger cultures of death and dying that we inhabit. *Being Mortal* explores the consequences of contemporary medical training that focuses primarily on “how to save life, not how to tend to their demise.” By fixating on “ensuring health and survival,” Western medicine has neglected palliative care, which works toward improving and maintaining quality of life for a sick or disabled person and their family. We have effectively worked to lose our vocabulary for death, a phenomenon now reducible to a “one thing after the other syndrome” or the great unmentionable circumscribed by trite truisms and Hallmark cards.

Gawande is rightly critical of medicine's own love of triumph narratives in favor of seeing advancements in prevention and treatment as progress at the expense of what Gawande hauntingly describes as a medical system that "has made it almost impossible to be sure who the dying even are." To put it even more bluntly, the medical gaze seems entirely uninvested in the dying, especially the dying who are marked as beyond medical intervention and the undiagnosable who expose the limits and flaws of medical knowledge. In Gawande's understanding, the crucial problem is a *temporal* one: standard medical care remains future-oriented (working "to extend life" for a "chance of gaining time later") while palliative care is presentist (invested in enabling the "fullest possible lives right now"). Thus, a truly compassionate hospice care offers, as Gawande beautifully puts it, "a new ideal for how we die," "an *ars moriendi* for our age."

As bioethicists have long critiqued, autonomy's reduction to simply choice of therapy or bodily ownership fails to account for other ways caregivers and clinicians can enable the wellbeing of those they serve. From a literary studies perspective, I found Gawande's invocation of Ronald Dworkin's conception of autonomy provocative for how it echoes similar moves in narrative medicine toward learning to attend to patient storytelling. Prioritizing this essential need and desire to "remain the writers of our own story" reads to me as a strikingly literary conception of life. This model nuances the purpose of palliative care beyond simply the alleviation of symptoms towards an honoring and preservation of patient narratives, be it in the patient history or even assistance with life-writing and memorial. With the "seemingly unstoppable momentum of medical treatment," as Gawande notes, there simply isn't space and time afforded for the difficult, necessary work of helping patients make sense of their new and disorienting experiences with sickness and disability (what Arthur Frank has described as "narrative wreckage"), let alone helping them and their loved ones preserve those experiences in narrative. If Susan Sontag has suggested metaphor can be violent and even detrimental to patient wellbeing, how might we empower patients to develop metaphors of their own, to crip the very military metaphors that Sontag identifies toward reparative ends?

At one point, Gawande asks, "if independence is what we live for, what do we do when it can no longer be sustained?" The medical establishment's insistence on preserving the right of an individual to *be* an individual through a "healthy" body here works toward the very detriment of that individual's wellbeing when that recovery becomes foreclosed or impossible. This point resonates with ongoing discussions among disability scholars and activists regarding interdependence and care. If we are all inevitably going to face disability, aging, and debility, we cannot see ourselves as permanently singular, autonomous, independent subjects. In fact, we might say we never were in the first place. *But can we have a palliative care that promotes interdependence without undermining autonomy as the right to one's own body? What does interdependent care look like?*

I return then to the circle of children and grandchildren by my grandmother's bedside now situated in the Fong family living room. The communal nature of my Chinese heritage, in some ways, has already prepared me to confront the ongoing questions I face regarding death and dying.

Maybe not answers, no, but the very truth that death, for my family at least, has never been about the individual. Rather it has always been a profound experience of the collective—never in isolation, the touching of generations again and again. We sweep tombs, light incense, burn joss paper, lay out meals because the dead have and always will be with us, for they always were us and continue to be us. To put it in Rilke's words to Franz Kappus, I don't need the answers now but instead need to live my way toward them *together*.

Gawande, Atul. *Being Mortal: Medicine and What Matters in the End*. Picador USA, 2017.