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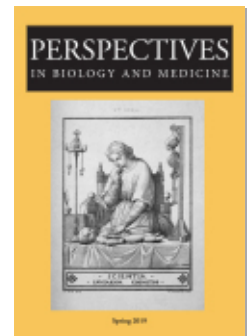
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The Patient as Professor: How My Life as a Person with  
Quadriplegia Shaped My Thinking as an Ethicist

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## THE PATIENT AS PROFESSOR

*how my life as a person with quadriplegia  
shaped my thinking as an ethicist*

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**BROOKE ELLISON**

I SHOULD NOT BE HERE. BY NEARLY ALL medical prognostication and statistical realism, I should not be here. In fact, anyone with any wagering savvy might have—and quite justifiably—placed her chips on someone else. But lives do not always adhere to probabilities, bell curves, or standard deviations. Personal will favors the long game over the short; determination and hopefulness strive for the less likely instead of the more—the extreme rather than the mean.

I have lived for 28 years with quadriplegia, a duration that is, in itself, far outside of the expected. However, the circumstances under which I became quadriplegic reduce the likelihood of this longevity even further.

It was 1990, and I was 11 years old. In what maybe I thought was idyllic or quintessentially American, I was walking home from my first day of junior high school in an unrelentingly charming Long Island town. The distance between my house and my junior high school was transected by a major highway where cars travel fast and pedestrians with trepidation. By foot or car, there was no way to get to my home from my school if not over this highway: the divide has since come to symbolize two different vantage points from which I now understand my life.

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I was hit by a car while I was walking home from my first day of 7th grade. Sometimes, to this day, I think I still hear the screeching of the brakes being applied to the car traveling 55 mph or the shattering of glass as my head hit the windshield. To this day, 28 years later, when traveling on that highway, I still look for traces of blood or sheets of looseleaf paper that may memorialize a point in my life that has been hazily etched in my memory.

From that day in 1990 and until several days later have been, for me, captured in narrative and lore much more than in actual cognitive memory. I was, by virtue of my accident, the victim of many crimes perpetuated by fate. I was, at once, in respiratory and cardiac arrest—without regular respiration or heartbeat. Couple this with what appeared to be extensive head trauma, nearly certain spinal cord injury, and innumerable broken bones, the status in which emergency medical responders found me was a veritable closed window on the likelihood of survival.

Fragile, profoundly injured, and nearer to death than I was to life, I was brought to the Trauma Unit of the Stony Brook University Hospital. It was a series of Herculean medical efforts that pulled me away from the precipice between life and the beyond. When you are a doctor treating a child whose life would otherwise end far too soon, or when you are the parent of a child whose life would end far too soon were it not for that physician, words like *futility* or *longshot* bear no meaning, take up no space in one's mouth. For better or for worse, my life didn't play the odds and knew nothing of futile.

My accident did not result in my death, nor did it leave me with damage to my brain, though both of these would have been likely outcomes. My accident did, however, leave me paralyzed from my neck down, with a subluxation at C2–3. I breathe only with the assistance of a ventilator which, 13 times per minute for 28 years, has pushed air into and out of my lungs through a tracheostomy. I get from place to place, event to event, classroom to classroom, and speaking engagement to speaking engagement with a wheelchair driven by pneumatic changes in air pressure that I apply to a straw. These are the logistical nuts and bolts of my life right now and, at one point, I would have thought this to be some kind of suboptimal, second-rate form of a life—some, I know, likely do—but making that assumption would be to evaluate a situation for its complexity rather than its virtue, to look at the messiness of a quadratic equation without trying to solve for its factors.

I have lived for 28 years with ventilator-dependent quadriplegia. Contrary to what many people believe or understand, this is a disability and not an ailment. Disability is not necessarily analogous with medical vulnerability, though it might sometimes involve it. According to many, a life like my own can fail to meet the arbitrary standard of a life worth living. Hollywood storytelling and medical history, alike, are laced with stories of the fallen hero—the individuals who would have led an idyllic life until they were bested by the despair brought

about by quadriplegia or immobility. It is thought to be unlivable because, in many ways, it is unimaginable—the ostensibly mummified soul, the trapped, the would-have-been.

I would be disingenuous if I were to say that this interpretation is surprising. We fear what we do not know, and there are few things more unknown than life lived without movement or sensation. It is a set of circumstances that no one would freely choose and most anyone would change for oneself. Yet many of the presumptions made about it, or the assumed experience pursuant to it, are frighteningly inaccurate and do little to advance the rights or quality of life for people who do, in fact, live in these circumstances. Third-party estimates of the relative difficulty of someone's life are notoriously inaccurate and can even have the unintended consequence of prescribing an outcome that is possibly irrelevant to the real, lived experiences at hand.

My quadriplegia is the result of a tragic accident that I was fortunate to survive. If one gains expertise through experience and exposure, our population of experts on death is small and fragile, but I count myself among them. The surprising consequence of a near-death experience is that, once death has brought itself near to you, it remains there, in your thoughts and in your personhood. Death is a rare life-guest that immediately overstays its welcome and stays anyway. It is almost as if a brush with death causes epigenetic changes to your DNA that become a part of your being and identity. It never goes away and remains long after the immediate risk of death has been alleviated, long after medical interventions have claimed their victory. There are times when I wish I could remember something—an image, a sensation, a perception—from the nearly two days I spent in the chasm between the here and the somewhere else, but my memory is as vacuous as what I expect that in-between to have been. There are no journal entries or holiday-snaps to spark my memory of the time I tiptoed the line between life and death, and I have no stories to tell about how close my consciousness came to becoming irreversibly unconscious, but the knowledge of having stayed there and flirted with death—even for a brief time—has breathed an ironic life into my thoughts and actions ever since.

I lingered in the undetermined space in between life and death for 36 hours, a duration that is interminably long for waiting loved ones yet brutally short when faced with decisions yielding long-term consequences. It is a time without feeling, a structureless existence with Daliesque surreality. But I awoke. I awoke to the alarms produced by the willful resistance I was forcing against a ventilator pushing air into my lungs. I have staggeringly vivid and detailed memories of the days I was willing my way back to life, perhaps only partially alive. I had terrifyingly little faith in the machine keeping me alive, understood each forced breath—coming either too quickly or not quickly enough—as a violation to my body and sensibilities. It is jarringly uncomfortable and unsettling to breathe in a mechanized fashion, at a prescribed rate, at neither a pace nor volume of your

own choosing, and I remember fighting against it, against what I perceived to be the most tangible and immediate foe I could try to wrestle to the ground. I was never taught to breathe without breathing or how to outsource the most fundamentally natural, in-house skill to someone or something else. I was never taught how the rhythmic and regulated pace of breath that lies at the foundation of meditation and serenity can feel anything but meditative or serene. No one tells you how it will feel, because essentially no one who is in the position to tell you has ever actually felt it. But what I was also *not* taught was that this machine, this foreign object that I intrinsically wanted to reject almost immunologically, was not my true foe, and that my will to fight was misplaced—misdirected when my will to fight needed to be reserved for the recovery ahead.

Recovery: a word uttered with justifiable trepidation in the medical field. Recovery: the logical antithesis of futility. Moving from unconsciousness to consciousness, intensive care to rehabilitation, I had no clear or even realistic idea of what recovery would look like for me on either a short-term or long-term scale. I understood “recovery” to be what so many of us understand it to be—a state defined by restoration and retrospective wholeness that can obscure the different or more modest changes that no less define recovery. I have not “recovered” from quadriplegia or ventilator-dependence, at least not in the way that many would reflexively interpret it. My body still lacks mobility and sensation below an indistinguishable point in my neck. My lungs still receive the air I need for survival through a tracheostomy operationalized through its yards of plastic tubing connected to a ventilator. These have not changed and, whether or not they ever will, bears no reflection on how I understand myself to have recovered.

“Futility,” “technological dependence,” “end-of-life decision-making,” this is medical ethics talk. But it is also disability talk. The field of medical ethics or bioethics and the world of disability have rarely been on especially friendly terms. Historically speaking, medical ethicists and bioethicists have debated and put philosophical parameters around the oftentimes unimaginably gut-wrenching experiences that people with disabilities and their families have undergone, in what some have understood to be intellectual theorizing about the very value or worthiness of someone else’s existence. While I understand that there is cynicism behind an interpretation like this, it is also not difficult to understand some validity in it, as well. The “nothing about us, without us” movement has its roots in the very same concerns: that decisions made about, resources allocated to, and judgments about the quality of life of people with disabilities ought not to be made—or at least not solely—by those who have not undergone the experiences themselves. But the field of bioethics is and should be much more diverse than that, asking fewer questions of “if” and more questions of “how.”

Now, 28 years after my accident, I am a professor of medical and science ethics at Stony Brook University. I straddle two fields and two worlds, one of disability

and one of bioethics, that are often at odds. The road I traveled from hospital bed to the front of the classroom has been long and, at many times, arduous. The very first step in this ever-evolving journey required me, even as a young child, to resist and redefine the societal indoctrination I was being administered—that a life like mine would never, could never, and possibly should never reach its potential. The belief I had in myself and my rejection of needless limitation were an essential part of the ammunition behind my fight to return to life as I had known it, fully immersed in my education and surrounded by my peers. This first step, which I took with admitted uncertainty, was an implicit battle against what seemed like very real extrinsic and intrinsic pressures to fall in line with commonly held beliefs about disability, people with disabilities, and their status in the world: that disability was both a personal and societal source of shame to be regretted or best done without.

Nevertheless, I knew I had a life to lead and a depth of experience to share brought about by my disability, and that this was not a source of shame but, instead, a source of societal enrichment. I had seen things that others had not seen and likely would never see, and the inclusion of this perspective was valuable, not detrimental. At 12 years old, when most children seek their mechanism of anonymity, I was looking for the opposite. This Renaissance of self was necessary, it was normalizing, and it allowed me to reorient the focus of my life from what I had lost to that which I still had. This first step eventually led me to Harvard University, where I did my undergraduate and masters work. My studies in cognitive neuroscience as an undergraduate and leadership as a graduate student delicately fused my desire to more deeply understand the diverse etiologies of disease and to adapt the understanding of disease and disability.

In this formative phase of my life, I never anticipated that my destination would be so identical to the origin. While pursuing my PhD, I became an advocate for the full spectrum of disability, from biomedical research on the one hand to human rights and the quality of life on the other. My research in the ethics and policymaking of stem cell science brought me deeply into applied ethics more generally, exploring how our theoretical ethical arguments about virtue and justice must be met with understandings about how these arguments affect people's lives in the most intimate ways. In my service on the Ethics Committee of the Empire State Stem Cell Board, I took part in complex philosophical arguments regarding the ethics of this research but, unlike many of my colleagues, I felt personally the immediate and agonizing consequences of the threat of that research being halted. I learned quickly that I could play a pivotal role in balancing the theoretical and the applied. I became aware that, if I had been fortunate or unfortunate enough to undergo some of the most grueling lessons and some of the most unimaginable circumstances life could present and then survive them, these would be meaningless if not translated into knowledge beyond myself. While I knew I would not be practicing medicine or science myself, I also knew

that, through my experiences and all I had learned about the phenomenology of medicine and disability, I could help others to become the best scientists and healthcare professionals they could be.

I became a scholar in the sociology of science and medicine, and I understand now more than ever how much scholarship demands a more diverse voice, and particularly how much science and medicine need the voices of those most affected by them. Before entering the field of medical ethics, it may have been the case that I did not even fully understand how many fundamental bioethical questions my life had encompassed. What was that much more unexpected was the need to develop the self-awareness to place my own anecdotal experiences with these questions into larger philosophical debates about them, balancing the applied and theoretical, the anecdotal and generalizable. But at the same time, much of bioethics and medical ethics lies in the anecdotal, in the classic cases, in the events that challenge that which is expected or is the norm.

Just as in any other general medical ethics course, in my courses we discuss comas and persistive vegetative states, and for many students, these concepts are as foreign and unrelatable as the most arcane theories of quantum mechanics. The assigned cases are riveting but remote, bafflingly personal and impersonal at the same time, and sometimes are presented in such a way that allows for analysis that favors a harsh medical calculus over a more human approach. In part because of this unrelatability and seeming irrelevance to their lives, many of my students have viewed the material initially as a purely medical aberration, sterilized and anesthetized like a preoperative protocol. Yet there are stories and real lives behind these concepts that are sometimes easily kept out of mind when they are not in sight. There are families like mine grieving with the weight of life's most agonizing decisions. So to complement the classic cases we read, I discuss what my family underwent when being told that their daughter and sister likely would not live or work nor have any ability to interact with the world, how the yearning to see one live and the unspoken hope for reprieve that immediately causes shame can exist coincidentally. I share how my parents were immediately thrust into a world they did not recognize and were exposed to a language they did not understand, as they tried to envision their lives either with or without their daughter. I share how my sister, brother, and extended family waited with contradictory hope and dread for news, knowing that even the best of news could only be so good. And, I share how a family can move forward—how the effects of a devastating accident or disease are felt across everyone in different ways but how they can ultimately become just life once again.

Just like in any other general bioethics course, in my courses we discuss physician-aid-in-dying, and how the right to end one's life at the time of one's own choosing has become so deeply enmeshed in debates about personhood, our societal visions of physical impairment, and our fundamental understandings of civil liberties. In the context of this discussion, each semester I ask my students—with

neither expectation nor judgment—their thoughts on what might constitute a life not worth living. Understandably, some students answer relationally, saying that they would not want to live without the comfort of friends and family. Invariably, however, there are many others who answer more tangibly and behaviorally, saying that they could not live if they were to lack independence, or if they could not engage in the physical activities that give their lives meaning, or if they were attached to machines and tubes, or even if they were paralyzed and could not use their bodies in the same way they had. Throughout the course of the semester, we invariably discuss the parts of disease and disability that are medical in nature, like physical pain, secondary infection, autonomic dysreflexia, and loss of function, and the parts that are societal in nature, like social marginalization, unemployment, poverty, and loss of independence. We discuss how the confluence of both of these types of factors impact an overall quality of life, and how the former can be managed or adapted to and how the latter can be alleviated if we, as a society, work to do it. In sharing what it is like to live with extreme physical limitation, I have seen many students evolve in their thinking and reach the conclusion that life can be and often is rich and full of meaning even when much has been lost. They come to the awareness that we can respect individual choice and autonomous decision-making, especially when life is reaching its conclusion, but that we also can work together as a society to provide opportunity and resources so that a life-ending decision is not necessarily the most obvious decision.

We also discuss the difficulty of delivering a life-altering diagnosis, how the phrase “currently untreatable” carries with it a graveness but not necessarily a hopelessness, and how delivering a diagnosis that respects both of these is a skill that can be mastered. I give speeches and presentations to medical students at the Stony Brook University School of Medicine, where I am an Associate Professor, describing the experiences I have undergone, how they have been impacted by my interactions with members of the medical profession, and how the goal-setting and determination I have had for my life has been supported by individuals who could understand struggles I have faced and assisted me in finding ways around these struggles. In a striking irony, the setting for these presentations and speeches is especially significant, as Stony Brook University Hospital was the medical institution that saved my life when I was a child. It is by virtue of these life events that students can see not only the product of medicine practiced successfully but also how even the successful practice of medicine is experienced and internalized by someone who receives it. These are key lessons—among the most important to my own recovery over the past 28 years—that are in no way included in medical or even bioethical textbooks, and these are lessons that health-care professionals ought to know. I share how, when one undergoes disease or disability, it is easy to feel as if the journey that is taken is a journey taken alone—that the diagnosis implicitly creates an isolation between a sense of normality enjoyed by most and



a sense of abnormality put on the shoulders of a penalized few. It is also easy to feel as though the magnitude of the diagnosis is all-encompassing, circumscribing every aspect of life at all times. Yet none of these assumptions is necessarily true; neither of these feelings of hopelessness is sequelae brought about by the diagnosis. While it is not the physician's given responsibility to change these perceptions of oneself in the context of disease, it is the hallmark of the exceptional physician.

This is applied and experiential learning, the significance of which has been lost on neither my students nor on me. In correspondence I have received over the years from former students who have gone on to become physicians, therapists, nurses, and professionals of various kinds, the writers have expressed to me how words and ideas written in a textbook had been brought to life and given far deeper, more nuanced significance through the voice of someone who had lived them. More importantly, they record how this directly influenced how they interacted with their patients, the kind of sensitivity they could bring to their interactions with them, and the knowledge that could shape their conversations.

But in my position as both patient and professor I have come to understand that I have also been a student. In my own personal reflections on my experiences as an educator, I have gained a new understanding and method by which to articulate the intricacies of my life. In this idiosyncratic intersectionality in which I reside, I have been forced to look at my own life through a sometimes uncomfortable bioethical lens, counterbalancing what I know to be true about my own life with what I also know to be true about many others'. I have worked to disaggregate personal anecdotal experience from generalizable occurrence while giving enough value to each to make them useful for future health-care providers. I have been challenged to think more deeply about the insidious ways that trauma affects our lives and about how we can become more resilient by putting trauma to positive use. These opportunities to think more deeply about questions that far too few ever want to think about at all have been gifts for my students and me, in equal measure.

It is rare that any one individual experiences such intensely personal medical ethical questions, like end-of-life decision-making, the hard calculus of medical futility, and the engineered but no less valuable life lived with technological medical dependence, and then lives to talk about it. It is far rarer, still, to experience these life-altering events but then proceed to teach and study it. That is an unfortunate yet understandable reality. Noted neurosurgeon Paul Kalanithi made the maddeningly true claim that the best way to understand death is to experience it. The challenge lies in the fact that almost no one experiences death and lives to tell about it. While there are many, though possibly not enough, personal accounts of the doctor-turned-patient, accounts of the reverse directionality are staggeringly uncommon. For me, it can be a unique and sometimes disorienting position to read scholarly works and articulately intellectualized theories surrounding com-

plex medical and personal decision-making that I not only experienced years ago but will continue to experience for the rest of my life. The life I lead and professional position I hold are dichotomous yet complementary. A bioethicist with a profound disability is a privileged yet unique position that has provided me with deeper insights about the experience of the patient in the most medically fragile condition, as well as deeper insights into how medicine can be better practiced. These are not mutually exclusive but, rather, collectively exhaustive vantage points, and the complementary nature of these seemingly polar positions has sat at the heart of my approach to bioethics as a professor and thinker. The science and art of medicine—the wisdom behind it and the care to provide it—are two halves of the same whole, two hemispheres of the brain, each of which has difficulty functioning to its greatest effect without the other. The duality of this relationship has been much easier to understand and then teach after having lived through it.

The questions I focus on both in my instruction and in my writing—how best to synthesize the care that patients want with the care that physicians provide—are two circles of a Venn diagram that do not uniformly overlap. When medicine becomes as central a part of one's life as it has to mine, you realize that there is an art to the practice, and a broad spectrum of excellence in this art. Since the advent of antibiotics, when the curative—as opposed to the maintenance—characteristic of medicine began to change, a movement towards health-care quality likewise became instantiated, with evidence-based practice and probabilistic diagnoses sitting at the heart. There is—and rightfully so—perhaps no one who would argue against the evidence-based and probabilistic framework in which medicine is practiced today. Great physicians know this, and many great physicians practice accordingly. Yet the true mastery of medicine necessarily includes but also exceeds the ability to make the best and most educated diagnosis the majority of the time. Excellence in the true art of medicine—as anyone who has spent significant amounts of time in the company of physicians can attest—lies also in the compassion and empathy they can offer their patients: the ability to perform life-saving medical feats but also to understand a family's grief and uncertainty while these feats are being performed; the ability to judge when life-support might be necessary but also the compassion to learn what a life lived on life-support is truly like; the skill to make a difficult diagnosis but also the sensitivity to deliver it with hope. In my years living through some of the most unenviable health circumstances, I know how important these conjoined skills are, how rarely they are jointly implemented, and how a new generation of physicians and health-care providers can embrace both without either sacrificing the other. Providing the best and right diagnosis for a patient sits alongside establishing the best, most compassionate, and most hopeful relationship with a patient. This is expertise also brought about by experience and exposure.

Many people could say that they would not be alive were it not for the advances of modern medicine, but I would not be here were it not for medicine at its most complex and aggressive. I am indebted both to science and to the medicine it produces, but who I am as an individual and what I have found the strength within myself to achieve is not the outcome of medicine, it is the outcome of compassion and empathy and fostering of hope when circumstances seemed bleakest. Though this may not be articulated in textbooks, there is no greater gift that a physician can provide to her patients.

This is a concept within medical ethics that perhaps does not receive the attention it deserves. When the primary and oftentimes preliminary questions of “futility” and “end-of-life decision-making” and “technological dependence” have been adjudicated, it is this additional piece of recovery and possibility that is not frequently addressed. This has real and important consequences for people’s lives, especially those who will live with chronic health-care conditions like disability. While presenting a diagnosis of reality there is also a prognosis of possibility, and it is on that vision of possibility that survivors will ultimately stake the rest of their lives.

I should not be here. That is a probabilistic statement, not a normative one. We are fortunate to live in an age when advances in medical technology and physician skill have made surviving with a disability the reasonable and expected outcome of any number of unanticipated life tragedies. But perhaps it is also an age when we can bring surviving with a disability into unity with living with a disability, and with all that living to one’s potential requires. I should not be here, but by the grace of medicine, I am. There was a point in my life when terms like “futility” or “life-support,” “critical care” or “brain-death” were mere shadows—redirected light without any experience to be attached to them. But now these terms are inseparable from the experiences that gave rise to them; they are given weight by the gravity of the life I have lived. My life has been one of deep meaning and purpose brought about by circumstances that, at the time, seemed meaningless and purposeless. Nothing has taught me more about recovery than has futility. Nothing has taught me more about life than has death. And there is nothing that has taught me more about probability than the unlikely. Hope lives in the unlikely and in the possible.