

ON THE BRAIN

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Seeing Ellen and the Platinum Rule

Several years before her death at the age of 55 years due to complications of cerebral palsy, my sister Ellen was again in hospital, this time in intensive care and on the brink of respiratory collapse and the possible need for intubation. To say cerebral palsy had shaped her life is an understatement, in that it molded nearly every facet of her being, from the contours of her body to the way she saw and experienced the world. And based on this, while one might assume that her life was defined by suffering, the only ones who suffered were those whose toes she managed to crush under the mighty weight of her electric wheelchair when she was on the dance floor.

With the passage of time, her body became increasingly contorted, affecting her ability to take a deep breath or fight off upper respiratory tract infections. So long as I can remember, blowing out birthday candles was impossible without the assistance of her nieces, nephews, friends, or extended family. Time at the family cottage in Winnipeg Beach, ice cream on a summer's day, chocolate milk, or meals prepared by my parents were among her greatest pleasures. But health challenges often interfered with her various plans and wishful thinking that one day she might actually get to see the world.

While being in hospital with Ellen was not an unfamiliar experience, this time felt different, with life and death hanging perilously in the balance. The attending physician, whom I knew from occasional work-related encounters, was diligently reviewing her medical record, scanning her monitors, and calculating if her deteriorating condition would soon require inserting a breathing tube. At one point her physician turned to me, asking "Does she read magazines?" While this was a seemingly innocent question, it was the only question I was asked about her personal life. The subtext was chilling, as this was not an attempt to get to know Ellen as a person or how she spent her days, but rather a cryptic way of deciding if hers was a life worth saving. While it was never said, I could intuit the rational and detached mental calculus. *Her body looks like a train wreck. Who would want to live this way? Perhaps we'd all be better off by letting nature take its course.*

To be clear, this physician was not a bad person and was regarded as a highly skilled clinician. But the lens through which my sister was being viewed was one that had been shaped in ways her physician was entirely unaware of. From the time we are young, there are images and values that are elevated above all others, including youth, beauty, wealth, and power. We learn to worship at the altar of this ephemeral perfection, with all else deemed of lesser value, lesser utility, and lesser consequence. The results are insidious, from the way we perceive bodies—our own and those of

others—to the social policies we do and do not support. It is no coincidence that older individuals, for instance, have been disproportionately affected by the COVID-19 pandemic, given our chronic failure to invest in the supports needed to safeguard their well-being and vitality. You bankroll what you value, and some lives are simply valued more than others.

But something else was happening that day at my sister's bedside that threatened to undermine the care she desperately wanted and needed. Treatment decisions are often based on considerations of reciprocity and The Golden Rule. *If I were that patient, what would I want for myself?*—doing unto others as we would want done unto ourselves. This means using our own values, wants, and needs as an indicator of those we assume are held by the patient. But what happens when these don't align? It is hard to imagine a wider chasm between my sister's lived experience and outlook, and that of her intensivist. When this degree of misalignment occurs, it is easy to anticipate health care recommendations based on the conviction that *I wouldn't want to live that way? I wouldn't want to be that disabled, dependent, disfigured, or disenfranchised. Why offer opportunities to sustain an existence that I would personally find unimaginable and intolerable?*

This is where a new standard of person-centered care—The Platinum Rule¹—comes into play: do unto others as they would want done unto themselves. This means not presuming that we know what is in the patient's best interest based on what we would want in their circumstances and taking the time to consider what they would want, hope, or wish for. While not every patient request can be accommodated, The Platinum Rule provides insights that strip away biases and assumptions, helping us see who patients are as people and raising the bar on person-centered care. Not being seen erodes human dignity and undermines personhood, experiences that are at the core of human suffering.²

So when Ellen's physician asked me if she read magazines, I scrambled to come up with a response that would have this physician see beyond her distorted body and failing lungs. There wasn't enough time to talk about jiving on the dance floor or Winnipeg Beach or birthday celebrations. I wanted Ellen to be seen as not just the patient, but the well-loved sister, daughter, aunt, niece, cousin, disability rights activist, and friend. I wanted everyone to understand that she had a rich emotional life, and an imagination that could take her to places that, as fate would have it, she would never get to see. And so, after a few seconds I responded, "Yes, she reads magazines. But only when she's in between novels."

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Conflict of Interest

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