On suicide

Twice have I wanted to die.

Against the force of gravity, I can move only a few fingers. To function in the world, I rely upon a high-tech wheelchair, a ventilator, suction machine, feeding pump, hydraulic lift, and human support for every intimate aspect of self-care.

The first time I wanted to die, I was a teenager. I was being fitted for a new wheelchair. My neck muscles were increasingly floppy. A secure headrest would ensure that I stayed upright. Everyone agreed that the wheelchair should be equipped with a headrest. Everyone, except me.

I was devastated. A headrest was a game-changer. In every photograph, in every mirror, in everyone's direct view as they looked me in the eye, a headrest would be there, declaring me frail and freakish. Headrests were for people who lived in institutions – they signaled the train-wreck case. I was not a *headrest cripple*. My body was in ruin, but my head was intact. I would die, before submitting to the humiliation of a headrest.

I recall my parents bewildered by my histrionic wailing. Still, they relented. No headrest. A young and hip and attuned orthotist built a custom brace that was discreet and effective. I grew my hair long, and convinced myself that for the most part, people wouldn't notice the thin aluminum shaft that supported the back of my neck for years. Years enough for me to encounter, befriend and respect lots of very cool, good-looking and good-living *headrest people*.

The second time I wanted to die, my reasons were less specific. I was in my mid-20s. I was living independently, well-housed, well-situated, well-supported. I had an active life and good friendships. But I was desperately lonely, lonely in deep inarticulate ways that I would only understand years later when the gift of loving intimacy made me whole.

I contemplated suicide. There were not many options. Pills, razor blades, weapons – all of these required a dexterity that eluded me then, eludes me still. Still, I formed a plan. On a cold winter night, under cloak of a few plausible lies, I would retreat to a dark place of hiding, and succumb to exposure.

The plan alone sufficed.

Thirty years later, I understand that the lines that we draw around personal dignity and quality of life are deeply personal. And because they are personal, they are often fleeting. Because they may be fleeting, our attention to them must be tentative, wary perhaps, shaped by caution.

Sometimes, our choices as private beings have public implication. Systems of law and ethics must have regard for those larger public dimensions, even as they aim to protect individual liberty. If we authorize suicide assistance in the face of impairment, we elevate ***shame*** to game-changer status. We reproduce humiliation as an ever more pervasive social harm, inscribed through the taboos of culture upon headrests and bedpans and feeding tubes.

It is true that impairment restricts the menu of means for the execution of will. But a limited menu is a menu nonetheless. Do not quickly underestimate the ingenuity and resourceful capacities of disabled persons to get the job done. Step back, settle your own fears and antipathies, and restrain the impulse to end our misery. Accord us first respect, not as abject selves, but as equals in all measure of quality and worth.

In our frenzy to extend individual control over the precise time and method of dying, let us not delude ourselves that we are defending the equality rights of disabled persons. Equality for disabled persons demands, alongside of social reforms, a deep cultural reimagining that as bodies decline, dignity remains intact. Equality demands supports for living, not haste in dying.

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