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Tired of Coping, Fed-up with Modern Medicine: Why the Long-term Chronically Ill and Disabled Should Have the Option to Die with Dignity

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Disability activists aim to create an environment in which disabled people are able to value themselves just as they are, as individuals endowed with extraordinary bodies, exceptional gifts, and unique insight. There are some, however, whose specific type of disease or impairment(s) makes it nearly impossible to reframe illness or disability in positive terms, no matter how much attention is given to social reengineering, legislative reform, or attitudinal modification. Although most disability activists oppose euthanasia, the author explains why a commitment to core humanist moral principles entails offering a dignified means to die to any who, without regard for proximity to death, are nearing the threshold of just how much pain or loss of bodily integrity they can bear.

keywords: euthanasia, chronic illness, disability, autonomy, humanism

Since Oregon's Death with Dignity Act was ratified 22 years ago,[1] seven states and the District of Columbia have adopted similar statutes just during the past decade. Many more have created euthanasia legislation that will be debated and/or voted on this year[2] or has yet to go into effect.[3] This flurry of recent bills on physician assisted death testifies to our growing desire to decide how the final months of our lives will play out, should ever we find ourselves terminally ill and enduring unbearable, irremediable pain or a loss of bodily integrity. The chief criterion for assessing eligibility in each state is that a patient must have a disease or tissue damage that is likely cause death within six months. The degree to which one is suffering, or the length of time one has been subjected to intolerable pain or compromised agency, are ancillary criteria.

But just across the Atlantic, countries such the Netherlands, Belgium, and Switzerland have adopted legislation where the level and duration of one's suffering play the decisive factor in determining whether one is eligible for euthanasia. And wisely so, because proximity to death does not always correlate well with the intensity or frequency of a patient's pain. To be sure, a terminal disease will always give rise to some discomfort and loss of agency, but the experience is not always as excruciating or debilitating as we are led to believe. There are people who have coped with, say, multiple sclerosis, inflammatory bowel disease, treatment-resistant depression, peripheral neuropathy, severe back pain, fibromyalgia, or phantom limb pain over decades whose suffering *on balance* far exceeds that of many patients who have just been informed they have less than six months to live. If one feature of any humane society is a commitment to relieving gratuitous suffering wherever possible, then progressive nations of the E.U. such as those noted above certainly qualify. We, on the other hand, have come up short.

Nevertheless, because of the recent surge of interest in maximizing autonomy during the final chapters of one's life, and because existing euthanasia laws both here overseas have not resulted in abuses predicted by opponents, we are well-positioned to introduce legislation that would include long-term chronically ill and disabled persons who have persevered through unimaginable suffering over many years, are utterly exhausted, and ready, as Susan Gubar (2017) has put it, "to lay down arms." Contrary to what many Americans may believe, some of us really do find ourselves in situations where we can anticipate only increasing pain and further degeneration, and the effort we expend to make it through each day no longer justifies the few paltry scraps of equanimity or pleasure that occasionally come our way. Some of us really do arrive at a point where hope runs out and life amounts to little more than endurance.

If in certain European nations citizens can have sophisticated conversations about granting the right to die with dignity to those who are simply tired of living,[4] to people who feel as if they've completed their life's work and have no further aims to satisfy,[5] and to elderly persons suffering not from disease or serious tissue damage but merely the ordinary pains and losses that come with aging,[6] surely we can discuss allowing the long-term ill and disabled to request assistance in dying. The time is ripe to move this conversation outside of the academy into the public forum.

1. Moral Principles and a Précis of the Argument

Although it would be desirable to explain in detail why I have selected the ethical principles I have, none are unfamiliar to readers of this journal, so I will simply state them as briefly as I can before outlining the argument and defining two key terms.

As a humanist, I take for granted that maximizing our chances at happiness generally involves:

> A. Awarding citizens as much autonomy[7] as we reasonably can. This principle is based on the assumption that individuals are best positioned to determine what lies in their interests, a conviction concisely articulated in the following way by J.S. Mill:

> "The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm from others. His own good, either physical or moral, is not sufficient warrant. ... The only part of the conduct of anyone for which he is amenable to society is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. *Over himself, over his own body and mind, the individual is sovereign*."[8]

This is not to say that we do not seek guidance from other people we respect or who have special expertise in a given field of inquiry, or that we derive insight from our cultural inheritances. Rather, because no one else has access to our total subjective experience of living in this world, only we ourselves have the capacity to discern which values and aims are most suitable at any given stage of our lives.

B. Acknowledging and showing respect for the diverse values and pursuits of our fellow citizens, so long as they do not lead to behaviors that would injure or infringe the rights of others. By "showing respect," I essentially mean assuming a *laissez faire* posture. One certainly need not find others' values and aims interesting or even especially laudable. Indeed, one has little control over how one feels about others' preferences. Much in the same way that our beliefs are formed involuntarily in response to perceptions, testimony, and argument, our feelings about others' important goals also arise as if on their own. Nevertheless, it would only seem fair that if we expect others to grant us the latitude to pursue goals we find worthy, we ought to extend latitude in similar measure to our fellow citizens.

C. Creating institutions, legislation, and policies that will help relieve as much gratuitous suffering as our current bodies of knowledge and technologies allow for. On a personal level, the corollary would entail sympathizing with others' pain and misfortune and drawing upon this sympathy to help alleviate their distress whenever possible—should, of course, they desire our assistance. If one is favorably inclined to virtue ethics or to certain religious traditions, one might rather choose to call this "living compassionately" or "loving one's neighbor."

The argument, which is grounded on these core principles, may be stated in the following way:

1) If, as noted above, it is true that many long-term ill and disabled persons reach a point when they are no longer able to cope successfully with their pain or loss of agency, find that their will to persevere is nearly extinguished, and hope for an improved quality of life has run dry, and;

2) if we are committed to maximizing autonomy during all stages of our adult lives, respecting others' values and aims, and alleviating needless suffering, then

> 3) we have good reason to offer the long-term ill and disabled an infallible, pain-free, dignified means to die, should they request such means while still of sound mind.

The prevailing alternatives are incompatible with our core convictions. If the long-term ill and disabled are not included in euthanasia legislation, they have little choice but to continue suffering until impersonal bio- and electrochemical processes finally put an end to consciousness, to try to end their lives with crude measures that traumatize and stigmatize survivors, or to risk employing suicide methods with low or unpredictable success rates—which, should they fail, are likely to leave them in even worse shape than before, and may preclude any further attempts at dying. This is the unenviable position in which many today find themselves. We ensure that our pets die with dignity, and even that objects like U.S. and state flags or copies of certain scriptures no longer fit for use are put to rest with dignity, yet we refuse people for whom "living on, in the only way they can, would disfigure ... the lives they had created" a dignified means to die (Dworkin et al., 1997).

What I propose to do is explain why some long-term ill and disabled people fear the prospect of continued existence, and are therefore deserving of the same peace of mind extended to the terminally ill, and why Americans are better positioned than many may think to offer them the option of dying with dignity. I will also address disability activists' understandable hesitation in endorsing such a position as well as a rather odd incongruence between firearms regulation and current euthanasia legislation that may be used to garner support for the generous measure of autonomy I think we ought to have over the timing and manner of our death.

2. Defining Key Terms

Before proceeding, it is important to differentiate between how two terms in particular—illness and disability—are employed in the academy and in everyday speech. When scholars who adhere to the social model of disability speak of impairment, disease, or tissue damage, they are referring to anatomical features or to bio- or electrochemical processes that stand outside of a statistically defined norm delineated by Western medicine. In many cases, these variations or "deviations from the norm" leave an individual open to stigmatization, marginalization, and discrimination. As Susan Wendell (2001) concisely puts it, disability is "socially constructed disadvantage based on impairment," disease, disfigurement, or dysfunctional cellular processes (22). As a social construction, we are the ones responsible for this disadvantage, generally because we have not taken the time to consider what it might be like to navigate our spatial environment, our social, educational, and municipal institutions, or our public policies with an impairment or chronic disease. But precisely because it is our doing rather than an intrinsic feature of our social landscape, it may also be minimized or even eliminated with assistance from those who have years of experience trying to gain access to the same opportunities and privileges the abled-bodied take for granted. By contrast, disability in common usage is often (mis)taken to refer to the impairment or tissue damage itself, exemplified by statements such as "She has a disability" or "His disability prevents him from driving."

In the academy, illness is generally taken to mean an individual's total subjective experience of disease, tissue damage, impairment, and/or pain. As Malcolm Parker points out, one is not ill unless one also disvalues something about their disease or impairment, or about the social consequences that stem from having a disease or an impairment (2013, 99; see also Wendell 2001, 20-23). This negative experience may originate primarily from unpleasant symptoms related to one's condition or to external factors such as loss of employment, exclusion from certain social networks, or the inability to participate in activities that bring meaning and joy to one's life. In everyday usage, however, illness is often taken to refer to a specific disease, as in statements such as "She has a terminal illness." What we really mean here is not her subjective experience of living with a specific disorder, but rather the disorder itself. We (mis)take illness for the set of cellular processes that ultimately will cause her death. Throughout this paper, I will use disability and illness as these terms are employed in the academy.

One of the difficulties disability activists face in reframing impairment or disease as mere human variation is that many who are chronically ill and suffer from features of their disease that most anyone would experience as unpleasant—acute pain, persistent fatigue, bouts of nausea, fits of coughing—are also disabled. Put differently, it is those who are both chronically ill *and* disabled who frustrate activists' attempts to deconstruct punitive stereotypes of the disabled as aggrieved by their limitations, as envious of able-bodied persons who cruise through life facing few impediments, or as incapable of doing (most of) what the able-bodied can do—live independently, earn a terminal degree, find rewarding employment that suits their unique skills and talents, develop vibrant, satisfying social lives, and so on.

Susan Wendell's distinction between the healthy and unhealthy disabled is instructive here. For her, the healthy disabled are those "whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future," and therefore "do not need or seek much more medical attention than other healthy people" (2001, 19). When disability activists speak of reconceptualizing impairment as variation rather than aberration, they generally have in mind Wendell's healthy disabled. It is the unhealthy disabled who create trouble for activists and scholars of disability.

According to Wendell, the unhealthy disabled never quite achieve stability, and so often find themselves bracing for the next flare or surge in pain, the next injury for which they will have to make that dreaded journey to the ER, or, worst of all, the next time they must be admitted to the hospital. It should come as no surprise that persistent undercurrents of anxiety and dread begin to affect their overall mood, interpersonal relations, work performance, familial obligations, as well as their willingness to accept any duties or social engagements beyond what is necessary. Even during periods of remission or relative calm, anxiety and fear do not magically disappear, and life does not return to normal. Traumatic memories from past flares or injuries rise to conscious awareness without warning, and they may worry whether they will have the resources and emotional resilience to manage whatever symptoms arise next. They often find themselves haunted by an unpredictable future, even if it is felt only vaguely as a knot in the stomach, as migrating myalgias in soft tissues, as muscle tension in the shoulders and at the base of the skull, or even as outbursts of anger or rapid descents into despair.

To put the matter more precisely, because Wendell's unhealthy disabled often face an unforeseeable disease trajectory, and never feel as if they can't quite settle in and relish those moments of reprieve during relative stability, they find it difficult to view their bodies positively. They feel as if their bodies have assumed an adversarial role, threatening to thwart their every effort to attain some semblance of equanimity. Where many healthy disabled people have good reason to celebrate their extraordinary bodies and resist Western medicine's inclination to normalize or "fix" them, most unhealthy disabled people cannot, and would gladly accept a cure if one were available. I will address this problem specifically as it relates to euthanasia below.

3. Illness and Disability as an Aversive Experience

> *The loss of my legs enraged me. It would always enrage me. And I would never get used to it.*
>
> – Leonard Kriegel

As noted above, contrary what to many Americans would like to believe, some who have been ill or disabled for an extended period do in fact reach a point where they can expect only further decline and increasing pain, and there is little to no reason to anticipate any improvement in their quality of life. This not just true of those nearing death. It can happen at any stage in a person's life, and when this insight finally hits home, it often gives rise to feelings of hopelessness and despair, and may even awaken recurrent suicidal thoughts.

In their book *Families Living with Chronic Illness and Disability: Interventions, Challenges, and Opportunities*, Paul Power and Arthur Dell Orto include an illness narrative authored by a woman who has been struggling with MS for many years. She writes:

> Flare-ups filled me with bitterness and despair. ... It is difficult to have a sense of contentment when experiencing physical and emotional discomfort. ... What works today does not work tomorrow. ... It is all very unpredictable. Words such as planning, goals, and objectives do not define multiple sclerosis. Multiple sclerosis has its own agenda, leaving you with limited control. ... In the fight against multiple sclerosis, I feel I have no weapon. (2004, 63-66)

It is chiefly the disease's unpredictability that causes this woman such distress. She feels as if she is at the mercy of unseen forces that may wreak havoc without warning, and she worries whether she will have the means to cope when new symptoms arise or familiar ones escalate. But she is also frustrated by the extent to which MS compromises her agency. Because the disease may undermine long-term planning or goals, she no longer feels as if she is the primary narrator of her own life-story. She is now forced to share this role with a malfeasant Other that neither knows nor cares about her important aims or well-being.

In her recent essay "Am I too Embarrassed to save My Life?", Jane Hamilton (2017) writes movingly about suffering from an aggressive autoimmune disorder that has generated unrelenting and widespread inflammation, which has resulted in "the wreckage of [her] physical life," leaving her a near-total shut-in. "Every day," she says, "with a disability is a bad situation from which I can't extricate myself. I'm feeble and vulnerable. If someone brandished a knife at me on the street and shouted, 'Run!', I couldn't. If I went to a protest and was pepper-sprayed or detained without access to my cardiac medications, I would promptly die, so I sit, mostly alone, on the border of life, watching others lead it." Hamilton feels that gradual losses of physical strength and mobility make her uncommonly vulnerable when venturing outside the safety of her residence. For her, disability is not something she can easily reframe in positive terms. It is, as she puts it, "a bad situation from which [she] can't extricate [her]self," one that has resulted in the demise of her social life and confined her to her home.

Finally, Leonard Kriegel's encounter with polio and the losses that followed offers a striking example of how even relatively stable impairments can elicit enduring anger and resentment. Kriegel contracted the virus when he was a boy, and although he retains a number of unsettling memories from his hospitalization and subsequent rehabilitation, it is the permanent loss of the use of his legs that accounts for most of his rage. Polio left him dependent on crutches to get around, which meant that many of the activities that brought joy to the "normal" boys in his neighborhood remained out of reach.

In his anthology of essays *Falling into Life*, Kriegel comments on an extended period of introspection that arose unexpectedly one evening while sitting alone in a café in Paris. "The reality I had lived with for twenty-one years," he writes, "had once again overwhelmed me. *I was a cripple*. And I miss the legs I had lost to a polio virus far more than I missed the wife and son I loved. The loss of my legs enraged me. It would always enrage me. And I would never get used to it" (1991, xii). While he takes pride in having achieved so much professionally in spite of his impairments, he nevertheless speaks of "the triumph of the virus," "the loss not merely of legs but of all those possibilities that might've been," and how "the rage created by loss ... lies behind each of the essays in this book" (xii-xiv). Although Kriegel would be categorized among Wendell's healthy disabled, he nevertheless had a predominantly aversive experience with his impairments. His body did not prove to be a rare and unique gift but rather an impediment to happiness, to experiencing many activities he otherwise might have with healthy hips and legs.

I empathize with each of these authors. Having lived with ankylosing spondylitis for thirteen years, I am well acquainted with persistent cervical, back, and joint pain as well as with increasing mobility restrictions. And having been subjected to a punishing chemotherapy regimen six years ago to address late-stage non-Hodgkin's lymphoma, I know what it is like to cope with the irreparable damage these toxins do to one's body over time. Like Jane Hamilton and the woman with MS, I can no longer participate in most of the activities that once brought me joy and meaning. I manage, cope, and persevere. I do not live. Terms like healing, rehabilitation, improvement, and hope are no longer part of my lexicon.

To have the assurance that I could die in a dignified manner that was pain-free and infallible, should ever I find my agency unduly compromised and my pain unbearable, would offer immense relief. But because I cannot access sedatives like pentobarbital or secobarbital, the only means I have for an early departure are either rather crude or have unpredictable success rates—which, should they fail, are likely to leave me in worse shape than before. Those of us who are weary of being a patient, and who are nearing the threshold of what we can reasonably tolerate, deserve better. We deserve the very same assurance the terminally ill receive in the few states that have enacted euthanasia legislation.

I share the examples above in part because they appear to undermine what scholars of disability and disability activists are trying so diligently to achieve: accommodation rather than corporeal (re)alignment with social norms, the generation of more positive and diverse disabled subjectivities in literature, film, and the media, as well as more opportunities to fashion rewarding lives in the absence of infantilization and discrimination. The Western medical model has traditionally seen its mission as rehabilitating bodies and minds so that they more closely approximate current cultural norms and ideal images of human able-bodiedness. But where Western medicine sees aberration or dysfunction, many disabled people see mere variation or difference. It is not the disabled who are broken or deficient and need "fixing," argue disability activists, but rather our ableist society that needs to broaden its myopic view of what it means to be human, to learn how to appreciate the great variety of physical forms and neural networks that constitute our species. Many disabled people take pride in their rare beauty and exceptional gifts, as well as the unique insight that comes from experiencing the world through a body that does not fit nicely within the statistically defined parameters that physicians deem "normal." They value themselves *just as they are*, and therefore seek not remediation but social and institutional changes that would empower them to have a fair shot at the pursuit of life, liberty, and happiness.

There remains one issue, however, that many scholars of disability are understandably reticent to address with full candor: the aversive experience that some have with impairment or disease that no amount of social reengineering, legislative effort, or attitudinal modification can help (Creamer 2009, 27, 89-90, 109-111; Shakespeare 2006, 202; Jeffreys 2002, 33; French 1993, 17-25).[9] The fact is that a rather large number of people who are ill or disabled find themselves unable to reframe disease or impairment as human variation, and when given the opportunity to write about their experiences, they often focus on what they have lost (or never had) and how they long for some semblance of equilibrium. In his study of autobiographical narratives authored by ill and disabled persons, G. Thomas Couser concisely articulates the problem:

> ... candid representation of some aspects of a condition may serve only to reinforce the assumption that disability is necessarily, wholly, and universally a negative experience. Indeed, there is no shortage of narratives that may backfire in this manner. ... Thus, the personal narrative of disability is by no means

> guaranteed to offer positive, progressive, and counterdiscursive portrayals of disability. (1997, 111)

Thankfully, many chronically ill and disabled people do find a way truly to "own" their extraordinary bodies, to reframe impairment or disease as mere variation (Betcher 2001, 347; Garland-Thomson 1997, 131-34, 137). But others remain ambivalent—grateful, on the one hand, for having received insight that could not have been acquired any other way (Kukla 2018; Fitzgibbons 2017; Wendell 2001; Price 1994), but also are willing to accept a cure if one were to be found (Mairs 1996a; 1996b). Still others experience disease or impairment in an entirely aversive manner, as an unwelcome intruder that awakens anxiety, anger, resentment, even despair. It is this latter group that remains largely unheard in disability studies today.

What few able-bodied people realize is that for some of us coping strategies[10] yield diminishing returns and the will to persevere wanes over time. Just as we deplete short-term willpower and require time away from our jobs, family obligations, and even our hobbies, so too does long-term willpower diminish as the years pass. Parents get time away from their children, employees receive time off from work, students receive breaks from their studies, and athletes often take months away in the off-season to allow their bodies to recuperate. But for the chronically ill and disabled, there are no holidays. Many never get even an hour off to relish what it is (or was) like to be free—free to lose themselves in a novel or roam about the countryside, free to accept a social invitation from a friend without first calculating whether the body is up to it, free to travel without first agonizing over whether all the preparations and lifestyle adjustments will make the trip worthwhile.

In a recent article in the *New York Times*, Susan Gubar (2017), who has been dealing with ovarian cancer since 2008, describes just how draining and demoralizing daily life with a chronic illness can be:

> Enormous energy must be spent getting to the hospital, completing paperwork, waiting for vitals and bloodwork and the oncologist, preparing for scans or radiation, undergoing infusions or transfusions, lining up at the pharmacy, and tackling insurance red tape. Periodically, surgical procedures further weaken a patient sent home with a drug arsenal to offset gruesome side effects—the most prominent being pain, nausea and weakness.

She fittingly calls the experience "treatment fatigue," likening it to combat fatigue, where the patient is the "soldier" and physicians and relatives are the high-ranking officers whose primary duty is to "rouse the demoralized foot soldier." Gubar is careful not to treat cancer as a special type of disease that either goes into remission, allowing the individual to return unscathed to her normal routine, or results in a death sentence, but rather as an illness much like any other. For those who grow weary of being a patient and come to realize that their future involves only further decline and further pain, she has this to say: "While dealing with a chronic or terminal condition, some people decide to reject medical options that damage the life left to be lived. Those who cease and desist should not be considered cowards, deserters, losers or quitters. Conscientious objectors, they have made their separate peace—if not with cancer, then with their living and their dying." She concludes by acknowledging that although she is not yet prepared to toss in the towel, she nevertheless "honor[s] those who decide to lay down arms."

Gubar rightly suggests that our society's predominant response to "conscientious objectors" is to label them cowards or to shame them for abandoning their duties. There is a presumption among the healthy that the ill and disabled have an obligation to access the most recent technological and pharmacological developments and press on until the body finally gives out on its own. Because of how much Western medicine now has to offer, it is argued, there is little excuse for someone who is chronically ill or disabled to withdraw from one's social affairs and responsibilities, and no excuse whatsoever for giving in to a pathological yearning for self-annihilation. Indeed, if individuals like Christopher Reeve and Stephen Hawking can overcome enormous adversity to continue offering their time and talents to society, what have any of us to complain about? Or what of the thousands of veterans who have lost limbs or been badly burned who nevertheless go on to lead rewarding and productive lives? If they can successfully cope with their impairments or tissue damage, what excuse do any of us have for wallowing in self-pity over comparatively minor pains and losses? Anyone who falls short of these extraordinary people lack courage or are just plain lazy. The ill and disabled have a duty to reach out, take advantage of medicine's advances, and learn how to cope with their limitations so that they can remain productive members of society.

But because the able-bodied are epistemological outsiders to the experience of being ill or disabled, they are not well-positioned to dictate how we ought to feel or what we ought to think. If our will to persevere is gradually depleted, our zest for life wanes, and even our desire to live is extinguished, so be it. To demand that we *feel* differently is preposterous, and not unlike mandating that one love this man or that woman, or like this food or that film. Whether or not one possesses a strong desire to live is not open to *moral* evaluation. Disease or impairment has had its way with us, and sometimes what we see—and see clearly—is an ever more grim and unrewarding future in which losses accumulate and self-determination is increasingly compromised.

4. The Special Case of Chronic Pain

> *If life is only a matter of pain, the question is whether it is worth living.*
>
> – A.J. Vetlesen

Illness and disability are most likely to be experienced aversively when accompanied by lasting pain for which physicians do not have adequate treatment protocols. Whether episodic or persistent, untreated pain is next to impossible to reframe in positive terms. While few people complain too much about acute pain that physicians believe should soon cease, and for which analgesics are able to offer some sense of control, long-term chronic pain can awaken a wide array of negative affectivities that extinguish even the most basic human desires—to socialize, to create, to set goals, and so on. I am thinking here especially of gratuitous pain, persistent and intractable unpleasant sensations that no longer offer constructive behavioral change. After many attempts have been made to bring such pain under control, it is not uncommon to experience anger, bitterness, despair, and suicidal ideation (Wall 2000, 136, 153-157; Melzack and Wall 2008, 35-36). To be sure, there are those few, as Patrick Wall observes, "who have a built-in genius for coping" (164), but for most of us, it is at best unwelcome, at worst utterly demoralizing (2002, 157-164).

Many have tried to describe pain at its worst and precisely what sort of impact it can have on us when endured for too long. Elaine Scarry, in her seminal book *The Body in Pain*, writes that its sheer aversiveness divides the subject, who wakes to find an alien, inimical entity at war with one's "true self"—a "not me" that one desperately wishes to expel. Over time, it can become "the single broad and omnipresent fact of existence," obliterating "the contents of consciousness" and destroying the capacity for speech. Although pain is fundamentally unshareable, it remains "indisputably real to the sufferer," and therefore tends to open an unbridgeable chasm between the subject and even her closest confidantes. Scarry finds a fitting—and compelling—comparison in torture: "Perhaps only in the prolonged and searing pain caused by accident or by disease or by the breakdown of the pain pathway itself is there the same brutal senselessness as in torture" (1985, 35, 51-56). For anyone who does experience the body as a mindless, sadistic torturer, "transformed so thoroughly into flesh," she may, like Jean Améry, lose her sense of "trust in the world"'—a trust that often cannot be regained (1980, 40). Indeed, for Améry,

> torture has an indelible character. Whoever was tortured, stays tortured. Torture is ineradicably burned into him. ... That one's fellow man was experienced as the antiman remains in the tortured person as an accumulated horror. It blocks the view into a world in which the principle of hope rules. ... It is *fear* that henceforth reigns over him. Fear—and also what is called resentments. (34, 40)

For certain people subject to intense pain, the body is experienced as what Améry calls the "antiman," leaving in its wake deep resentment and an abiding distrust in corporeality as such, an irreparable breach in relation to the ground of one's very being.

In *A Philosophy of Pain*, Arne Johan Vetlesen offers a similar but even more poignant description of the kind of traumatic disruption severe chronic pain can introduce into a person's life. Like Scarry, Vetlesen also views pain as an uninvited, sadistic Other that robs the individual of the capacity for introspection and transcendence (2009, 7-57). This tyrannical Other gradually wears the patient down, "eliminat[ing] all rivals to [her] attention" so that "[t]he outward looking nature of the senses ... withers away" (51-56). Should this "alien and deeply hostile" invader succeed in transforming one's "whole being into immanence," narrowing one's world so that "existence is reduced to the body" and life becomes "only a matter of pain" (55-57), the question of "whether [life] is worth living" inevitably presents itself to the subject (7). This is so in part because such relentless pain isolates the patient from her support network and prevents her from participating in so many of the activities that once brought her joy (29, 55). Importantly, Vetlesen refuses to see "psychic pain" as less catastrophic than physical pain. For him, "psychic pain can be just as fatal as physical pain," because it too has the potential to extinguish our desire to remain involved in the ordinary affairs of our lives and to frustrate our capacity for equanimity and contemplation (43, 51-57). Research over the past half-century in particular has revealed that any neat distinction between the physical and mental has collapsed, so Vetlesen is justified in not awarding priority to physical pain, as all euthanasia legislation here in the U.S. (mistakenly) has.

Unfortunately, over the past several decades we have seen few major developments in treating pain. Not only have we made little headway in creating safe, effective, well-tolerated pain medications, but "aspirin and opium together are responsible for at least 95 percent of the analgesic medicines used today" (Melzack and Wall 2008, xii-xiii; Wall 2000, 111, 171). Moreover, recent anesthetic and surgical procedures for severing nerves or creating lesions in parts of the brain believed to process nociceptive stimuli have produced unimpressive results. Relief is generally either temporary, or in cases where nociceptive pathways have been interrupted surgically, nerves tend to regenerate, and when they do, they sometimes create even more pain for the patient in the long run (Melzack and Wall 2008, 106-145, 171). Also, anyone who is taking pain medications routinely prescribed today—opioid derivatives, muscle relaxants, or even drugs originally designed to treat anxiety and depression—is well acquainted with the adverse side effects: somnolence, dry mouth, slowing of the digestive tract, impairment of cognitive and motor capacities, dependence, and so on. These effects are not to be minimized. In fact, they can so significantly impair one's thought processes and motor function that one is no longer able to work, to relate to others in customary and appropriate ways, or, perhaps most importantly, to feel at all like oneself.

5. Paternalism in Modern Medicine

> *All patients should undergo a comprehensive history including questions pertaining to suicide, substance abuse, and psychiatric illness.*
>
> – John W. Gilbert et al.

When we say that we are weary of being a patient, in part we mean that we are tired of finding ever new strategies of managing unpleasant symptoms and fed-up with all the tedium and frustration involved, as Susan Gubar (2017) put it, in "getting to the hospital, completing paperwork, waiting for vitals and bloodwork ..., preparing for scans or radiation, undergoing infusions or transfusions, lining up at the pharmacy, and tackling insurance red tape." But we are also increasingly infuriated by the paternalism inherent in our healthcare system. Although our bodies may be failing, and although our outward appearance may suggest that our mental faculties are not quite what they were, we are still fully capable of complex analytical thinking and of clearly articulating our preferences for the kind and amount of care we desire.

Over the past three decades, a large body of research has emerged that aims to better identify which attitudes and behaviors among the chronically ill and disabled are most likely to place them "at risk" for suicidal ideation (SI). The data reveal that those with a long-standing disease or impairment often exhibit negative states of mind such as perceived burdensomeness, thwarted belongingness, loss of meaning, diminution of self-esteem, and recurrent feelings of hopelessness at rates higher than what we typically find in healthy populations (Wilson 2013; Kanzler et al. 2012; Kaplan 2007 et al.; H Quan et al. 2002; Lokhandwala and Westefeld 1997). Understandably, patients who present with the highest levels of pain and the most challenging physical limitations are most likely to have suicidal thoughts (Kanzler et al. 2012, 603). None of these results should come as a surprise. Suicidal ideation is a natural response to persistent pain, increasing mobility losses, and diminution of autonomy, especially once one has arrived at the realization that her symptoms will only worsen with time.

The purpose of this research is not to better understand what it is like to live with a chronic disease or impairment, but rather to equip physicians to carefully "monitor" their patients so that they can intervene before a suicide attempt is made, either by referring patients out for psychiatric examination and treatment, or even by ordering an involuntary committal. Generally speaking, it is assumed that patients who present with SI have developed distorted views of themselves and the world and lack basic resources for negotiating life's difficult terrain. Because of these character deficits, they are therefore are in dire need of medical professionals' intervention. The literature is profoundly paternalistic: physicians position themselves as wise parents who always know what's best and their patients as an undifferentiated mass of simpleminded children who fail to see clearly.

For example, in their study of suicide and SI among noncancer pain patients, John W. Gilbert and his coauthors conclude that physicians should establish "universal precautions aimed at *monitoring* chronic noncancer patients [that] may deter, detect, and reduce suicidality. *All patients* should undergo a comprehensive history including questions pertaining to suicide, substance abuse, and psychiatric illness" in an effort to achieve full "*compliance* with behavioral health evaluations" (2009, 1970, 1976; italics mine). Because patients who present with SI have inaccurate perceptions of reality, they must be carefully monitored and strongly encouraged (or even forced) to comply with prescribed treatment regimens. Aberrant habits-of-mind are to be rooted out and gradually supplanted with life-affirming worldviews, regardless of whether physicians are in a position to offer patients anything that might actually diminish their suffering. The primary aim here is very simple: to prevent patients from taking their lives.

In their article "Exploration of the Relationship Between Disability Perception, Preference for Death Over Disability, and Suicidality in Patients with Acute and Chronic Pain," David Fishbain and his coauthors offer a similar charge to their fellow physicians: "Any PWCP [person with chronic pain] who considers himself/herself disabled could be asked as to how he/she feels about his/her disability status. Any response indicating a preference for death should then trigger questions related to passive, active, and historical suicidality or a request for a behavioral examination" (2012, 560). Although slightly less insistent than the authors above, for Fishbain et al. the chief objective does not change: to make sure that people who are suffering do not opt out of living—and again, regardless of whether physicians actually have any meaningful assistance that might improve their quality of life. Of chief importance is that lives are saved and prolonged.

Tasneem Lokhandwala and John Westefeld's "Rational Suicide and the Crisis of Terminal Illness" (1998) offers a rather mystifying, even jarring, reading experience, given that one of the authors was Director of the Counseling Psychology Ph.D. Program at the University of Iowa when this paper was published. They insist that even the terminally ill ought to cultivate the virtue of "resilience," "learn valuable survival skills," "search for reasons to live," and strongly consider "[a]lternatives to rational suicide," because after all "[i]t would be a shame ... when a treatment and/or a cure might emerge tomorrow." Asking a terminally ill person to develop "survival skills" and spend her remaining weeks or months wracking her brain for "reasons to live" in the hope that a cure might become available "tomorrow" defies logic and basic common sense. Their recommendations are all the more perplexing given the lead author's training and prestigious position. If they happen to be members of (conservative) religious communities, I suppose one might understand why they feel this advice might be suitable. If not, it is baffling why they would suggest giving the terminally ill the sort of advice one would ordinarily offer only to people who expect to recover and return to their normal routines.

Linda Jones's article "Anxiety, As Experienced by Chronic Pain Patients" offers a fine example of how chronically ill patients who present with SI are perceived to be character-deficient. "Pain-prone patients," she writes,

> tend to be passively dependent on others for emotional and/or financial support. They're usually depressed, in which case they show disgust, discouragement, irritability, tiredness, slowing down, feeling sorry for themselves, and even despair. ... If a person experiencing chronic pain is to cope with and learn to manage the pain, he or she must reach a point of accepting the pain and the accompanying anxieties ... and establish ways of constructing responses to reality. (1985, 217)

For Jones, SI is not a natural response of the mind to extraordinarily difficult circumstances but rather an indicator of poor character. The emergence of chronic pain merely exposes preexisting character flaws like passivity, dependency, pessimism, an inclination to self-pity, as well as an inability to cope constructively with the hard realities of human existence.

The tendency to infantilize patients in academic papers eventually trickles down to publications that reach a larger percentage of medical professionals. For example, in a colorful, visually appealing column situated on the left-hand side of a page in the "Clinical Digest" section of *Nursing Standard* (2014), there appears a brief summary of the research above under the heading "Some Physical Illnesses Linked to Higher Risk of Self-harm and Suicide." The idea, of course, is to arm frontline caregivers so that they too can keep an eye out for disorders that correlate most closely "with an increased risk of self-harm," ultimately so that "*at-risk* individuals may be better *identified* and *monitored* for any psychiatric symptoms and mental distress" (16; italics mine). Doctors are not the only ones who are to be proactive. Nurses too are to remain vigilant for the slightest hint of SI among their patients. Suspects are to be identified and referred out immediately to personnel capable of (re)instilling a life-affirming worldview.

On my desk sits a rather large stack of academic articles and essays—several, oddly, from the *New York Times*—that replicate the same self-assured paternalistic tone, one that positions medical professionals as guardians of truth and the chronically ill as a population especially vulnerable to erroneous worldviews. Rather than select a few more examples, I'll summarize what nearly all have in common. First, the assumption that suicide is wrong and ought always to be prevented remains unexamined. It is taken to be an objective truth that should be self-evident to their target audience—indeed, to *any* audience. Suicide is always an improper, if not morally impermissible or reprehensible, response to hardship. That this assumption is nowhere challenged with any degree of sophistication betrays a lack of awareness of the voluminous work in philosophy and ethics on elective death, which, on the whole, allows for a wide variety of circumstances that might render suicide morally justifiable. Second, authors frequently use terminology ordinarily employed with children or those believed to be intellectual or moral inferiors. Common examples include:

> a) labeling a patient a "suicide *risk*," which positions her as someone about to do something unlawful or irrational;
>
> b) continuing to use antiquated terms such as "*committing* suicide," which frames a patient's thoughts and/or behaviors as criminal in character;
>
> c) asking medical professionals to "monitor" a patient's speech and body language for any sign that she might be depressed or unusually anxious; and
>
> d) encouraging sometimes aggressive "interventions" that override a patient's autonomy and fundamental right to refuse treatment.

After spending a fair amount of time perusing this literature, I remain perplexed as to why physicians believe they are in a privileged position to render authoritative judgments about others' thought processes and worldviews. Are they privy to some profound existential insight to which the rest of us are blind? What special training gives them the right to dictate to "vulnerable populations" like the chronically ill and disabled precisely which experiences of the world are to be granted legitimacy and which are not?

Where physicians on the whole view SI as pathological and a likely precursor to the (self-evidently) immoral act of suicide, I see SI as a natural response of the mind to exceptionally challenging circumstances. And where physicians merely mirror society's unchallenged assumption that suicide is always wrong and therefore to be prevented, sometimes by forcibly overriding an individual's autonomy, I see suicide as a rational and morally justifiable response to long-term, intractable suffering that has become unbearable. Finally, where physicians often view people who present with SI as character-deficient—as misguided, weak, irresponsible and therefore in immediate need of intervention—I see them as having been given the gift of being of able to reflect on reality through a wider lens. We are not an especially "vulnerable population" whose thought processes and behaviors need to be closely "monitored." Nor are we especially prone to irrational or ethically questionable thinking, as most members of the APA and AMA uncritically assume. While SI arises involuntarily and may trigger a premature and tragic act of self-harm, it may also inspire the kind of calm, measured, lengthy introspection required to determine if and when elective death might be a suitable response to irremediable suffering. Fortunately, there are a handful of psychiatrists and psychologists (Lester 2003; Szasz 1980) who see their role as empowering people who present with SI to carefully consider whether this involuntary movement of the mind may offer a reasonable resolution to what truly has become hopeless suffering.

In 2019, there is no longer any excuse for this kind of epistemic arrogance and infantilization. Medical professionals have been talking for well over a half century about shifting away from authoritarian, paternalistic models to value(s)-based medicine (alternatively, collaborative or patient centered care), yet I find little evidence—empirical, anecdotal, or personal—that they have put these new approaches into effect on a broad scale. As Malcolm Parker observes, the field of bioethics in its infancy sought to provide "support for the diversity of values that were denied by medicine's core scientific paternalism" and establish "autonomy as the pre-eminent principle," which would require physicians to inquire about and respect "the needs, values, and circumstances of each patient" as well as take measures to safeguard "patients' rights to decide what medical treatment they will undertake or refuse" (2013, 99-101). In value(s)-based medicine, the physician is rightly recognized to be a knowledgeable and highly skilled technician whose job is to offer a diagnosis, an array of treatment options, and, if qualified, to begin a treatment regimen, *but only in a manner consistent with a patient's preferences*. If a physician feels uncomfortable with her patient's wishes, she always reserves the right to discontinue the relationship and refer the patient to someone else. But at no point is the patient bound to comply with a physicians' desires for her.

Patients have the right both to accept or refuse recommended treatment options and to discuss tailoring standardized protocols to suit their unique life circumstances. Physicians may understand the ins-and-outs of how a given disease "works," the various processes of cause and effect that give rise to a patient's symptoms, but only the patient has access to her subjective experience of being ill and how it affects her quality of life. Ultimately, all decisions regarding a patient's treatment are to be evaluated in light of her own preferences and goals, and all subsequent actions are to be authorized by her, free of any physician's attempts to influence her decision by, say, withholding important evidence about a given treatment's efficacy or side effects or failing to share all reasonable options, even—and perhaps especially—those for which a physician may have a personal dislike or may not have the requisite training.

6. Unsympathetic, Incompetent Patient Care

> *My cardiologist and internist were superb technicians, but they were completely devoid of any interpersonal*

> *skills that would enable them to relate to me as a person with feelings.*
>
> – David Lester

An aversive experience of illness or disability is often made worse when physicians do not provide competent, committed, compassionate care. Many chronic diseases are accompanied by comorbidities and have unpredictable trajectories, and therefore require physicians to think outside-the-box. At a minimum, physicians having difficulty addressing a chronically ill person's most troublesome symptoms ought to initiate *and* remain in conversation with other relevant specialists rather than simply making a referral. Of course, creative, sympathetic care requires more time and effort, and physicians who do wish to devote more resources to their patients often cannot because our current healthcare models are profit-oriented and therefore designed to maximize efficiency and minimize liability. In a system characterized by hurried consults (Verghese 2018; Ofri 2017) and orders for expensive diagnostic tests of dubious value, it is hardly surprising that patients' trust in their healthcare providers is eroding (Khullar 2018).

Physician Dhruv Khullar (2017) suggests that part of the problem stems from just how few doctors are—or have been—chronically ill or disabled themselves. As epistemological outsiders, they have no idea what it is like to navigate life "waist-high in the world," as Nancy Mairs (1996b) famously put it, or to be expected to feign wellness before colleagues, friends, and family members when one is in acute pain or near-collapse from fatigue. Nor do they understand what it like to journey from specialist to specialist in search of some way to bring one's symptoms under control or to contain one's frustration with physicians who refuse to modify standardized treatment regimens to accommodate one's unique employment and/or family situation. Among the most exasperating experiences is to spend hours carefully preparing a synopsis of one's medical history and most pressing concerns only to be interrupted within thirty seconds of an initial consult and then talked at—often from behind a computer screen—for the remaining ten minutes of the session. Most physicians are not aware just how much time, energy, and money their patients invest searching for some relief, for if they did, I doubt they would shuttle us out the door quite so quickly. And that is precisely Khullar's point: they *cannot* know, because the overwhelming majority do not understand chronic illness or disability *from the inside*.

One way to make sure the chronically ill and disabled receive the care they deserve is to increase the number of physicians who are epistemological insiders. Unfortunately, notes Khullar (2017), among those with impairments or chronic diseases who are accepted to medical school, attrition rates are high. Not surprisingly, studies suggest that the number of practicing disabled physicians is in the low single digits—perhaps as low as 2%—which is a far cry from the roughly 20% of Americans who live with an impairment, and an even farther cry from the percentage who would self-identify as chronically ill. One reason for the disproportionate representation is relatively easy to account for: the training required to become a physician is exceptionally rigorous, and many would not be where they are today had they not been able-bodied for the better part of their academic careers. The surest way to increase representation is to make reasonable accommodations for ill and disabled medical students—and, of course, after graduation for ill and disabled physicians.

Khullar suggests another rather unsettling reason for why the chronically ill and disabled do not always receive the care they need. Physicians understandably prefer clear-cut diagnoses for which we have successful treatment protocols. But for many who are chronically ill and disabled, these protocols are not always straightforward, especially when they involve comorbidities, and the interventions we do have are generally aimed at slowing disease progression or reducing pain rather than providing a cure or full restoration of function. Although it is understandable why some physicians might not feel enthusiastic about treating patients who anticipate only further decline, given the obscene amount of money many specialists make, one might hope they could make more of an effort to ameliorate their patients' suffering. Many physicians may not be consciously aware of this psychodynamic, but I suspect Khullar may be onto something.

If patients who do not offer the gratification of improvement or a cure too often receive insufficient or unsympathetic care, perhaps patients who show promise of a (near-) full recovery do? Not necessarily. In *Fixin' to Die*, psychologist David Lester shares his experience of two relatively brief stays in the hospital during which he underwent routine procedures on his heart and colon. At the time, Lester was neither chronically ill nor disabled, and physicians expected him to recovery quickly and return to his research and teaching, assuming neither procedure presented complications. This is what Lester has to say about his time in the hospital: "My cardiologist and internist were superb technicians, but they were completely devoid of any interpersonal skills that would enable them to relate to me *as a person with feelings*" (2003, 48; italics mine). Disheartened "by the lack of interpersonal caring (or even the ability to pretend to be caring) on the part of [his] physicians" (11), he remains unconvinced that changes proposed as early as the 1960s in improving bedside manner and incorporating patients' preferences into prescribed treatments have made their way into routine clinical and hospital care. Although he underwent both procedures in the mid-1990s, at the time he completed this monograph, he was not aware of any empirical evidence that treating the patient *as a person* with unique values, preferences, and life circumstances rather than a dysfunctional or damaged body in need of repair had been implemented on a broad scale (10-11).

Lester is even more critical of the state of his own discipline. Physicians who believe that assiduously "monitoring" chronically ill and disabled patients for any signs of SI and then referring out—or even involuntarily committing—those they conclude pose a "danger to themselves" are naïve to assume their actions will do much good. "Psychotherapy often does not work," concedes Lester, "or psychotherapists are sometimes incompetent, [and] medication does have side effects" (43). Of course, one reason why psychotherapy does not yield the results for which one might hope is that insurance coverage for intensive mental healthcare is very hard to find, a trend that has worsened since the publication of *Fixin' to Die*. Psychotherapy is most effective when a caregiver can develop a long-term relationship with a client, which means that it is often accessible only by those with "Cadillac" insurance plans or enough disposable income that would enable them to pay out-of-pocket.

For decades, it has been widely known that depression is closely correlated with SI. Because most psychologists and psychiatrists believe they have made great strides in treating depression, they also believe that we are better equipped than ever before to assist those who struggle with SI. Lester once again holds a different—and, I would suggest, far more realistic—view: “Unfortunately, when psychiatrists recommend treating the depression of suicidal people, their plan is usually to prescribe medication. They often do this in a cold, impersonal manner, with little or no discussion of the side effects of the medication and without taking time to get to know their clients and providing evidence [of the medications’ efficacy]” (45). When brief consults aimed at prescribing or altering medications are not accompanied by long-term talk therapy, it is unreasonable for referring physicians to expect psychiatrists to deliver the sort of outcomes they would like to see. Furthermore, most any patient ought to know that the mere mention of suicide during a psychiatric evaluation or counseling session can be very risky, since caregivers are required to report clients who pose “a danger to themselves” to local authorities (usually to the magistrate’s office). Even if one can find a caring therapist and has the means to pay for long-term treatment, many patients would (wisely) be reticent to discuss SI with them anyhow for fear of giving the impression that they intend to act. Because some patients really do reach a point where their most unpleasant symptoms are only expected to worsen, and because compassionate, effective mental healthcare is so hard to come by, Lester therefore concludes “that people who are suicidal may have little reason to expect a better quality of life if they continue living. I do not think it is irrational for them to expect that circumstances will continue to be bad or even get worse and to decide that there is no other alternative to suicide” (43-44). Lester courageously acknowledges what few in medicine are willing to admit.

Instead of merely criticizing his colleagues, however, Lester has chosen to redefine the therapist’s role when treating patients who present with SI or who already have a concrete plan for terminating their lives: “The task of counselors and psychotherapy should be to help you make up your mind about whether and in what way you want to die ...” (7). Although he hopes clients can find good reasons to persevere, and perhaps even flourish once again, he refuses to force patients to adopt a major worldview shift that does not reflect their experience. Rather, he believes his role is to help patients clarify precisely which issues are contributing to SI, to identify any false beliefs they may have about these issues and the part they play in generating SI, and finally to assist them in weighing the benefits and harms of taking their lives, should they choose to do so. Once these objectives have been met, Lester takes a step back and allows the patient to decide which alternative(s) are best suited to her personal preferences and life circumstances (54). Forcing a patient to remain alive once she has carefully weighed the options and clearly articulated reasons for why dying is preferable to living strikes Lester as not only as futile and cruel, but also as an unjustifiable violation of her autonomy.

7. An Incongruence between Firearms Regulation and Euthanasia Legislation

One of the most formidable arguments opponents of euthanasia must face is why we Americans pass out firearms to just about anyone who wants one (or several) but refuse a chronically ill or disabled individual a single fatal dose of a sedative that would permit *just her* to die with dignity. Most of members of Congress are not the least bit troubled by this glaring discrepancy.

On the one hand, Congress has ensured that nearly every citizen has easy access to guns, including military-style assault rifles and high capacity magazines. Existing laws allow gun owners to take kill large numbers of people in mere minutes, should they so desire. We should hardly be surprised, then, that a young man from a small town in Connecticut was able to procure weapons and enough ammunition to unload 154 bullets at an elementary school in minutes, killing over twenty kindergartners, teachers, and school staff members before first-responders could even get a clear sense of what had transpired. As I write this essay, Congress has yet to enact any meaningful gun regulation, which is one reason why mass shootings since the massacre at Sandy Hook have continued to occur at a rate higher than in any other wealthy industrialized nation. On the other hand, our representatives will not even entertain the possibility of bringing to the House or Senate floor legislation that would allow chronically ill and disabled people whose intractable suffering has sapped nearly all joy and purpose from life the assurance they could opt out with dignity if ever their pain or incapacity became too much to bear.

What is perhaps more perplexing is that the terminally ill who are residents in one of the few states that allow for euthanasia must first meet a far more rigorous set of criteria before qualifying for physician assisted death than any background check ever conducted for a firearm permit—a permit, as noted above, that would allow its holder to kill numerous people, none of whom (presumably) wish to die. If Congress has no qualms whatsoever granting access to guns to most anyone who wants one, surely it can bring to the floor a bill that would allow someone who believes that continued existence would disfigure her remaining months or years to request a single fatal dose of a sedative.

8. Resources for Moving Forward

Fortunately, Americans are well-positioned to open a pathway to assisted death for the long-term chronically ill and disabled. For instance, the six moral and political philosophers who authored the widely cited *Philosophers' Brief* (1997) on euthanasia[11] argue that the Constitution and a large body of judicial precedent stipulate that among our most cherished values is "to live *and die* in the light of [our] own religious and ethical beliefs" (italics mine). Although not all citizens would regard decisions about "the timing and manner of one's death" as "momentous," some clearly do, and they ought to be free to determine how their final months unfold rather than to allow impersonal processes decide the matter for them. Certain people, it is argued, "want to end their lives when they think that living on, in the only way they can, would disfigure rather than enhance the lives they had created," and they "must not be forced to end their lives in a way that appalls them, just because that is what some majority think proper."

The position taken here is staked on the more general principle that because only individuals can know what truly lies in their best interests, they ought to have the freedom to shape the course of their lives as they choose, so long as they do not harm or unduly infringe the rights of others in the process. And for the authors who submitted this brief of the amici curiae, our fundamental liberties are not to be stripped away just because we are nearing life's end and may appear to others as if our capacity to reason in accordance with our most deeply held convictions is somehow impaired. Enervation, bodily incapacity, or stretches of pain that exceed the limits of what most of us can endure do not necessarily equate to diminished faculties of mind. As long as a patient has not waited too long so that she is no longer competent or of sound mind, she retains the generous measure of autonomy guaranteed to her under the Constitution. No well-intentioned family member, friend, or physician has the authority to override her preferences for when and how her life ought to end.

Furthermore, in an article titled "It's My Body and I'll Die If I Want To: A Property-based Argument in Support of Assisted Suicide," Roger Friedman unpacks constitutional and legal precedent for the claim that "one's own body is one's property," and that therefore "the rights of property ownership should attach to the human body" (1995, 197). If true, as I think he successfully shows, then we can also appeal to "property rights" over our own bodies to defend our "right to assisted suicide" (197).

Although Friedman examines the work of philosophers as well as numerous judicial rulings that contribute to our understanding of self-ownership today, for our purposes the most concisely formulated statement can be found in Cruzan v. Director, Missouri Department of Health: "... '[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every free individual to the *possession and control of his own person, free from all restraint or interference of others*, unless by clear and unquestionable authority'" (212). The nod to a full-bodied autonomy, to our right to pursue what we believe lies in our best interests, so long as we do not also use our bodies in ways that unduly infringe the rights of others or hinder their search for happiness, is unambiguous.

Friedman also observes that even if legal precedent should not be as evident as it is, Americans nevertheless proceed on the assumption that each of us has been granted ownership rights over her own person. Examples include the option to refuse medical treatment and that no part of our body may be "harvested" postmortem without our consent. So, based on judicial precedent and common practice, Friedman confidently concludes that "property rights do exist in body parts and whole bodies," which means that death with dignity advocates can employ a "property-based argument [to provide] suffering people the legal and moral ammunition to exercise their rights to commit suicide and have others assist them in doing so" (212-213).

Admittedly, there are drawbacks in using such an argument today, *but not quite so many that we should abandon it altogether*. Many Americans of the twenty-first century, for instance, would find the notion of a person holding property rights over their bodies both offensive and incoherent. It offends by making the human body—an indispensable component of what constitutes a person—as a mere thing among just so many other things. "Things," of course, can be bought and sold for a price, and their value is determined relative to other things with similar features, capabilities, and so on. Most Americans—and certainly all Kantians—would at least profess to believing that a person is of inestimable value, "beyond all price." Indeed, when it comes to persons, it has long been anathema to speak of a *specific* value at all.

The language is incoherent in light of recent work in the academy, which has shown that the mind is inseparable—indeed, entirely dependent—upon the body. Mind-body dualism, whether of the religious or more sophisticated neo-dualist varieties, has lost its cache among philosophers as a whole. When we speak casually of "having the right to do what I want with my body" or "stipulating what I want my loved ones to do with my body when I die," we unwittingly fall back into a dualistic understanding of the person, as if we were essentially spiritual beings temporarily united to this dispensable husk of flesh, blood, and bone. But the sciences have buried this view. Like mainstream creationism, mind-body dualism may *feel* correct intuitively, but it is not supported by the data, which suggests that our "minds"—shorthand for highly complex, organized bio- and electrochemical neural activity—emerges from and is entirely dependent upon the body. What we have come to experience as an "I" or "me" develops slowly over many years as a result of complex processes that take place within our bodies and between other bodies, all of which play out within a specific set of social and cultural discourses. The feeling I have, then, of being somehow unified and invariant, a discreet and enduring ethereal "I" who was deposited within this transient body, is an illusion. It is therefore incoherent to say that complex neural activity within the brain should somehow come to "own" the remainder of the physical stuff that constitutes my body.

Technically, neither we nor anyone else can "own" us, for there is no one superhuman being or group of such beings who have created us, whether with preexisting material or *ex nihilo*. We are rather the product of impersonal trial-and-error processes—mutation and natural selection—that have been at work for billions of years. However, we may argue that there are countless individuals who can claim a small *stake* or *share* in us because they have contributed in some way to our development. They would include, for example, our parents, friends, teachers, and acquaintances, but also our favorite authors and television personalities—all those who have shaped our minds through the transmission of cultural discourses and the *grands* (or *petits*) *récits* within which we find meaning. But they would also consist of people responsible for sustaining and safeguarding our bodies—farmers, laborers, truck drivers, and grocery clerks, as well as the medical professionals who contributed to our successful entry into this world and enable us to survive injury and disease.

So, because countless others can claim to have contributed to the development of our minds as well as the growth and preservation of our bodies, any one of them might legitimately claim to have an investment, however small, in who we have become. But no single person or entity—no jealous and retributive sky god, no king or queen, no slaveowner, no parent or guardian, not even we ourselves—can claim full unadulterated ownership. The best even we can do is claim partial or shared ownership. Nevertheless, as part of our (multiply amended) social contract, we have decided to confer full ownership rights upon one another as a kind of noble fiction, presumably because we believe that it is best suited to maximizing our chances at happiness. Although neither I nor anyone else can truly claim to own me in full, I am nevertheless more than happy to draw upon this language to support more progressive euthanasia legislation. Far too many people suffer needlessly at the moment for us to await a shift away from antiquated terminology that is both morally unappealing and out-of-step with how we now conceive of persons.

9. Conclusion

The long-term chronically ill and disabled who experience disease or impairment aversively deserve to know they can end their lives in a peaceful, dignified, infallible manner should ever they find themselves facing intractable and unbearable suffering. Many have suffered, or will suffer, far more on balance than individuals who, because of disease or extensive tissue damage, are expected to die within six months. This is due not only to pain, loss of bodily integrity, compromised agency, or the diminishing efficacy of coping strategies, but also to years of having to put up with infantilizing and often unsympathetic treatment in a profit-oriented healthcare system that aims to maximize efficiency and minimize liability. At the moment, their only options are to entrust themselves to the care of strangers and allow impersonal bio- and electrochemical processes to decide the matter for them, employ crude measures that would needlessly traumatize survivors, or risk using suicide methods with unpredictable outcomes. None are consistent with the moral principles identified at the beginning of this essay. The first effectively undermines their autonomy when they need it most, and the other two create needless anxiety and may significantly augment the suffering of an individual who attempts to die but fails. If we value autonomy, compassion, and minimizing gratuitous pain wherever possible, then a bill that includes the long-term ill and disabled who are nearing or already have reached their threshold for pain or indignity would seem warranted. This is, frankly, a relatively "safe" concession. It is not as if I am proposing a bill that would include, say, minors without age restrictions, which Belgium's Senate and lower house of Parliament approved over five years ago.[12]

But ratifying more progressive legislation such as we see in certain countries of the E.U. is not feasible now at the federal level, in part because we remain such a deeply religious nation, where rhetoric of appealing to the divine will still prevails among so many segments of the population. There may be ample constitutional and legal precedent to move forward, but culturally we are not ready. This is our unfortunate but hard reality. However, states like Oregon and Washington, which between them have over three decades of successfully implementing death with dignity laws, and whose residents have become accustomed to civil discourse over this issue, are well-positioned to take the next step. Perhaps one day soon, if secularization continues at its current rate, these states will also take the lead in discussing whether reasons such as life fatigue or the ordinary pains and losses that come with aging might qualify for physician assisted death as well.

I'd like to offer two closing thoughts not addressed in the body of the essay. It is widely known that healthcare administered during advanced stages of chronic and terminal diseases is often very expensive. Should someone who desires an early exit rather see savings and assets transferred to loved ones or charitable organizations rather than to corporations and individuals who have more than enough as it is—insurance and pharmaceutical companies, hospitals, physicians—euthanasia legislation that includes the long-term ill and disabled would enable them to direct resources as they so choose. What often occurs during late-stage illness is a massive transfer of wealth from the lower and middle classes to those who already have more than their fair share. This is not a phenomenon we like to talk about, but socially conscious individuals who are ill or disabled may want to mitigate the continuance of this injustice, if even only on a very small scale. The best way to rectify this grievous wrong on a broad scale is to adopt some form of universal healthcare, which regrettably will not be considered a viable option by a majority in Congress for years to come. But the proposed change to current legislation would at least allow people with late-stage illnesses to take a stand against this maddening phenomenon and offer a final gesture of beneficence to those they love.

Finally, no one should have to press on indefinitely in excruciating pain or deprived of nearly all agency just to prevent friends and family members from feeling sad. If this argument is raised (as it almost always is), it does not proceed from love, but rather from self-interest and fear. The emotional distress that others feel in the wake of a loved one's death not only fades with time but also pales in comparison to the years of intractable suffering many chronically ill and disabled persons have already endured. Love respects the wishes of the beloved, desires what is best for the beloved, and certainly cannot bear to watch the beloved suffer unbearably without hope of reprieve.

Notes

1. After a three-year delay due to judicial challenges, the bill finally went into effect on October 27, 1997.

2. These states include Arizona, Arkansas, Connecticut, Delaware, Indiana, Iowa, Kansas, Minnesota, New Mexico, New York, Pennsylvania, Rhode Island, Utah, and Virginia.

3. New Jersey's law became effective in August 2019 and Maine's in September 2019.

4. There is, for instance, the now famous Dutch case in which an 86-year-old man named Edward Brongersma successfully persuaded his physician to assist him in dying because of "life fatigue" (Huxtable Möller, 2007 117-119). Mr. Brongersma had not been diagnosed with a physical or mental illness. He was simply tired of living and had no further important aims to fulfill.

5. The Dutch case of Mrs. Boomsma is illustrative, although it also includes elements of the so-called "loss of meaning" rationale. Having divorced her husband and lost her two sons, she no longer felt as if there was anything worth living for. Her entire identity had been constructed around her role as a mother, and when that role was no longer available, "she found her life empty and vain" (Wijsbek 2012, 3). "Her children," writes Henri Wijsbek, "had been all she lived for, all she cared for, ... and she could not replace them by anything else" (3). Or, as Mrs. Boomsma's herself put it: "I have lost all I had and I shall never get it back again. It would be good for me if I too could die. I don't want to become another person than the one I was when I was a mother" (4). Like Mr. Brongersma, she too was able to persuade her doctor to write her a prescription for a fatal dose of a sedative.

6. Perhaps the most widely known example is "Drion's pill," named after Hulb Drion, former V.P. of the Dutch High Court, who proposed as early as 1991 that older people whose various health issues, none of which could be classified as a terminal condition, had so diminished their quality of life that they saw no point in continued existence. This (hypothetical) pill would allow them to exit life peacefully on their terms, before their bodies and minds had degenerated so far that they would have little choice but to await whatever cellular processes finally put an end to consciousness.

7. By autonomy, I essentially mean having at one's disposal a wide array of choices one may access to satisfy one's needs and desires. An autonomous person would therefore not feel compelled to follow others' orders without recourse to refuse or resist, nor would she feel driven by inner compulsions over which she has no control (May 1994, 141). Beate Rössler helpfully adds that an autonomous person should also be able "to account to herself *why*, in particular decisions where personal decisions were made, she has chosen some possibility and not another, and wanted to live in one way rather than another" (2002, 144-145; italics mine). Critical, of course, to the exercise of agency are a number of external factors, including one's political context, cultural mores, and social class. An autonomous individual, for instance, would have the good fortune of living in an open, free, democratic society whose legislative and judicial branches allow for a generous measure of self-expression. She would also benefit by being raised in a progressive household that encourages critical thinking and draws its core ethical principles either from secular sources or religious communities that welcome recent advances in the academy. Finally, she would need to secure enough disposable income to allow for higher education, travel, and sufficient free time to think carefully about how she wishes to structure the narrative of her life. Given that we live in an increasingly deregulated capitalist economy marked by ever-increasing economic pressures on lower- and middle-income families, the latter criterion is becoming harder to satisfy.

8. The quotation from Mill's *On Liberty* is taken from Groll (2014, 198; italics mine).

9. Of the four authors listed above, Tom Shakespeare puts it most concisely when he says that even in a barrier-free utopia "there remains disadvantage associated with having many impairments which no amount of environmental change could entirely eliminate" (202). For some, then, the disabled body is experienced as having "*intrinsic* limitations" (202; italics mine).

10. "Coping strategies" refers to the diverse ways by which the ill and/or disabled manage unpleasant features of their disease or impairment(s). Generally speaking, they are understood to be *intentional* attitudinal and behavioral modifications that patients use to compliment standard treatment protocols recommended by physicians, although some scholars focus on ways in which we unconsciously—and often destructively—deal with chronic illness through, say, denial or substance abuse.

11. This brief of the amici curiae was submitted in response to the U.S. Supreme Court's decision to offer a ruling on the constitutionality of two states' prohibitions against physician assisted death.

12. I should acknowledge that I do support Belgium's euthanasia laws. However, here in the U.S., there is little point in fostering conversations about implementing legislation like theirs in the public arena. Such discussions would merely ignite the wrath of the G.O.P's religious base and impede progress currently being made by death with dignity advocates.

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