

## A respectful postscript to Edward Hung's end-of-life letter

What can be done to weaken the lethal grip of the notion that life must be lived full-strength or not at all

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**By:** Catherine Frazee Published on Sun Mar 30 2014

Edward Hung's [compelling letter](#) about his battle with incurable ALS and his choice of assisted suicide in Switzerland to end his life rekindles a debate that, on the surface, appears to pit reason and compassion against stubborn indifference.

A respected Toronto lawyer, Hung framed his closing argument skilfully and persuasively: better to permit hastening death than to require the prolonged suffering of terminal illness.

Truth be told, it is difficult to argue against the plain sense proposition that a person of Hung's stature and determination should be supported to die on his own terms, in the manner and place and time of his choosing.

And yet, there are those who must respectfully dissent for reasons that are neither stubborn nor indifferent, but instead arise from a different framing of the core question. We know that private acts have public consequences. To frame the issue at stake in this debate as one of individual liberty and choice diverts attention from the deeper question of how our laws and social policy respond to human vulnerability and decline.

From the Oregon experience, where physician-assisted death has been legally sanctioned since 1994, we have a clear picture of the reasons why people choose it. Oregon's 2013 Death with Dignity Act Report indicates that "as in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (93 per cent), decreasing ability to participate in activities that made life enjoyable (88.7 per cent) and loss of dignity (73.2 per cent)."

Much like [Dr. Donald Low's video](#), Edward Hung's letter is a compelling reminder of the human

dimension of these statistics. Hung's plea presents an honest articulation of a profoundly human concern. But as we grapple with this deep and pressing concern, peering through the tunnel of individual rights leaves a larger landscape invisible.

One essential feature in this vast social landscape is disability. Each day of our lives, disabled people like me do battle in a world that prizes all that we are not. Our struggles to claim some sense of place in this world are not won by sheer force of will and character. Rather, those of us who succeed and thrive do so in small enclaves of honest regard and fearless embrace. In such enclaves, the slings that lift us, the tubes that feed us, the instruments that fill our lungs with air and empty our bladders of urine are understood as tools for living, rather than as markers of spoiled life.

Granted, disabled people — myself included — have had years to embrace dependence, time to adjust our expectations of tired old organs, to work out management strategies, to train and nurture caregivers among whom we can be sure of reciprocal respect. We have had the opportunity to cultivate a mature stance on diapers and tubes, to adjust to conditions of life that terrify others.

We appreciate that not everyone has that luxury of time and opportunity when diagnoses come fast and out of the blue, when decline is merciless and rapid.

Entire lifetimes are invested in fear and contempt for the accoutrements of disability. Who can turn on the dime of life's imminent end?

No one. And that is the crux of the matter. Those years of allegiance to a myth of human life as robust and self-reliant are irreversibly debilitating. Like an opportunistic virus, this pernicious and pervasive myth joined with ALS to shorten Hung's life.

No faint words of solace or philosophy will loosen the grip of dread when this great myth fails. Only the fragile ecology of equal regard can sustain us. In the presence of family and friends who are at ease with our diapers and tubes, we can peel back the layers of shame that erode the will to live.

Thus a vital social ecology is gravely threatened by policies that accept uncritically the proposition that severe physical incapacity strips life of value, dignity and purpose. Canadians who cannot move or swallow or bathe or breathe or speak independently know that this proposition is both false and dangerous.

And our very survival depends upon your knowing it, too.

Edward Hung answered the question that plagued his final months in the best way that he could imagine. For this, he has my respect. For those of us he leaves behind, however, a very different question begs response.

What can we do — what must we do — far upstream of catastrophic diagnoses to weaken the lethal grip of the notion that life must be lived full-strength?

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