

SUBMISSION TO
THE SPECIAL JOINT COMMITTEE
ON PHYSICIAN-ASSISTED DYING

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Honourable Members of the Joint Committee,

I have watched with great interest the webcasts of your hearings with stakeholders and subject-area experts as our national conversation about physician-hastened death continues into its legislative phase. I commend each of you for your obvious commitment to the important task before you and thank you for ensuring the accessibility of your proceedings for all who wish to participate.

I regret that the Committee declined my request to appear before you in my individual capacity, separate from my role with the External Panel. Of course I accept and respect that decision: the Committee has very little time, and must make difficult choices with respect to the management of that time.

The report of the External Panel speaks for itself I believe as a comprehensive digest of our in-depth consultation discussions in Canada and internationally. I hope that you have found this report helpful, as well as your discussions with my colleague and co-author, M. Benoit Pelletier. I know that I speak for M. Pelletier, as well as for our panel Chair, Dr. Harvey Max Chochinov, in our expression of continued support for your Committee's work. I trust that you will not hesitate to reach out to us at any time in your process if there are clarifications or elaborations we might provide to assist in your task.

I do not propose to revisit our report to any extent in this submission, for it strikes me that what we heard as the External Panel is consistent with the input that your Committee was able to hear directly in its brief process. Rather, what I wish to offer in this written submission is a distillation of my own reflections on the subject of human vulnerability, and on the question of what is demanded of us in the design of a regime for physician-hastened death that truly takes human vulnerability into account. I offer these reflections as a Canadian who has lived all of her life with a significant physical disability, and whose work has centered upon the recognition and protection of human rights for all persons disadvantaged by discrimination and inequality. A particular focus of my teaching and writing in recent years has been the problem of precarious citizenship – when disabled persons are systematically denied social and cultural power. It is from this frame of reference – informed, of course, by my term of service with the External Panel – that I offer the following thoughts about safeguards appropriate in a country such as Canada that accords constitutional primacy to the principle of equality “before and under the law”.

1. Understanding and Assessing Vulnerability

To be vulnerable, quite simply, is to be without defence.

For some persons – infants, toddlers, persons with extensive and severe impairments – vulnerability may be intrinsic to their condition of life. Without muscle to flee or resist, without words to request or refuse, without art or philosophy to reinvent or transcend, such persons are nearly fully at the mercy of the other.

Yet even in these most seeming absolute expressions, vulnerability presents itself by degrees. The infant born in Oshawa in 2016 shows herself in fact to have robust defenses, compared to the infant born

simultaneously in Aleppo, Syria. Likewise today's toddler with Down syndrome from Kamloops is doubtless far less vulnerable than was her counterpart in Hadamar, at the peak of Nazi rule in 1941.

Vulnerability is as much a matter of context as it is of personal condition. In this way, for each and every one of us throughout life, vulnerability is situational, experienced when our defenses are stripped away.

Paradoxically, we are all vulnerable, yet many do not **know** vulnerability. For the most part, it remains an abstract notion about which we have little visceral intuition. Without conscious attention to the mounting of protections, we have matured into adulthood and accrued the means to feed and clothe and shelter and keep safe our fragile and needy bodies. We acquired skills and knowledge, we built strength and savings and social networks, we found homes, jobs, love and meaning. And so we are not without defence – we have locks on our doors, clothes on our backs, food in our refrigerators, numbers on our speed dial.

Supporting these simple phases of our “independent” adult development, are of course massive commitments of public investment and regulation – a veritable arsenal of defense to shield us from our human vulnerability: systems of health, education, job creation and public works. Most of us do not need to attend to our own vulnerability. When we adjust the thermostat, flush the toilet, place our garbage at the curb, the state takes over. When we purchase raw poultry, cross a busy intersection, install a new smoke detector, the state has our back.

If we are vulnerable but don't know it, that is because the social contract is working in our favour. Only when our defenses fail – Walkerton comes to mind, or the Ice Storm of 1998 – do we experience the full force of our vulnerability and urgently scramble to our backup defenses: hospital emergency rooms for the sick, friends with woodstoves and generators for the cold and hungry. Again we find rescue, buoyed from the turbulent waters of crisis by our firm grip on the social determinants of health.

Understanding the all-important role played by the social determinants of health in inoculating us from the experience of human vulnerability is an important first step as we turn our minds to the task of building a system for assisted dying that meets the standard the Supreme Court has set for us in its Carter decision. As the American feminist legal scholar Martha Fineman explains, because “we are positioned differently within a web of economic and institutional relationships, our vulnerabilities range in magnitude and potential according to the quality and quantity of resources we possess or can command.”¹

It is for these reasons that advocates from disability rights and other sectors have argued for procedural safeguards in a framework for assisted death that would assign explicit responsibility for evaluating the impact of vulnerability as a critical phase of the assessment of a request for assisted death. Such a mechanism would require determinations not only of an individual's medical condition and cognitive capacity, but also and equally, a skilled assessment of the particular context surrounding the request. To rely upon the conventions of “standard medical assessment practice”, it is argued, demands of physicians a more nuanced understanding of poverty and disadvantage than is reasonable to assume, given the focus of their training and the reality of their privileged position in the social order. The safeguard most frequently referred to as “vulnerability assessment” recognizes that the detection of

vulnerability may not be immediately apparent to persons richly endowed with the social determinants of health. A precautionary step that requires a moment of stepping back from the patient's presenting medical condition to consider the surrounding social condition would seem a prudent approach to ensure that the "sea change"ⁱⁱ of medically hastened death does not adversely impact persons disadvantaged both in relation to the social determinants of health and in many cases, in relation to the institutions of medicine themselves.

2. Understanding and Promoting Flourishing

If vulnerability is the experience of being without defence, it follows that people experience vulnerability when they are deprived of that which defends them – the resources that permit them to survive and flourish. At first thought, questions of flourishing may seem unrelated to the work of a Committee mandated to focus on providing the means for assisted death when human suffering is enduring and intolerable. On the other hand, when we are better protected from vulnerability, we are less likely to suffer intolerably. That is not to say that our suffering is reduced, but rather that our tolerance for it is boosted.

A 74-year-old man living with the devastating effects of ALS – ventilator-dependent, paralyzed and unable to speak – uses a single remaining muscle in his cheek to communicate, at the rate of one word per minute, his passions for cosmology and theoretical physicsⁱⁱⁱ. A 22-year-old athlete completes over 5000 km of a grueling pan-Canadian marathon before succumbing to the cancer he wants to spur researchers to beat^{iv}. A 62-year-old artist diagnosed with Alzheimer's disease paints persistently, producing a series of intimate portraits and self-portraits, until he can no longer hold the implements of his work^v. A woman enduring the unbearable grief of her son's suicide returns quickly to her office job for the comforts of collegial normalcy.^{vi}

These are NOT stories of individual heroism, much as they are often cast in that light by our celebrity culture. Not one of these individuals, or others whose triumphs we may personally know, would hold themselves out as extraordinarily courageous or virtuous^{vii}. To be sure, there is a thread of fortitude, a clarity of purpose running through each of these scenarios. But from that point forward these stories are propelled less by character than context as each individual – Hawking, Fox, Utermohlen and an anonymous grieving mother – each by circumstance and persuasion, manages to rally assets sufficient to endure great suffering.

The rallying of assets – material and social – renders us resilient to the experience of vulnerability. When conditions are right, when our social determinants of health are intact, when we are valued and welcomed and supported, when we are permitted and empowered to do with our lives what we most desire, human beings have proven ourselves time and time again to be resilient. Flourishing can and does occur in the final stages of terminal disease, at the most advanced states of irreversible decline, and among people who are desperately ill. Research has demonstrated, for example, that patients with terminal cancer who receive palliative care immediately upon diagnosis report significantly improved quality of life, are burdened less by pain and other symptoms, experience less depression and have a longer life expectancy.^{viii}

An important study from Oregon by Ganzini et al., concluded that “interventions that help patients maintain control, independence, and self-care in a home environment may be effective means of addressing serious requests for PAD.”^{ix} Throughout its process, the Joint Committee has heard forcefully and consistently from groups and individuals on all sides of the assisted dying debate, that the provision of quality palliative care must be recognized as an essential medical service in Canada. The External Panel has reported similarly that Canadians need and want universal access to palliative care, in addition to a comprehensive system of disability and home supports^x. Given the evidence of the effectiveness of palliative medicine in supporting resilience at end-of-life, and given our legislative obligation to shape social policy around the vision of promoting resiliency for all Canadians, these calls belong squarely in the realm of necessary safeguards for the implementation of a framework for physician-hastened death in Canada.

The Cultural Dimensions of Vulnerability

People with fewer resources at their command, people unable to marshal the assets that build resilience, are prone to experience the full force of their vulnerability when calamity strikes. This fact is well known and now thoroughly documented by the World Health Organization and other monitoring bodies^{xi}. Less well understood, however, is the impact of the experience of sudden vulnerability upon persons who have enjoyed social and material privilege and security. Experience in Oregon and other jurisdictions with permissive approaches to physician-hastened death suggests that those who advocate for and actively pursue this option tend to cluster demographically in privileged social groups. In her testimony before the Committee, Ms. Maureen Taylor, co-chair of the Provincial/Territorial Expert Advisory Group, reflected that “... in Oregon,... the vast majority of patients who ask for physician-assisted dying and get it are the three W’s: white, wealthy and well-educated, and it is not the socially vulnerable who get there.”

I cannot purport to know the extent to which this fact ought to have bearing in the design of a framework for a Criminal Code exemption around physician-hastened death but I do believe we must be mindful of its potential significance. As Ms. Taylor noted, it is possible that such patterns may point to barriers to access for disadvantaged groups. On the other hand, others might argue that the socially privileged class is not the group to entrust with the ranking of policy priorities affecting life and death, or to finely calibrate a system that protects the vulnerable from harm. Further investigation of the machinery of privilege in the context of assisted dying would be illuminating, but in the absence of extensive sociological analysis, I would venture the following reflection.

For persons who have enjoyed lifetimes of physical vigor and social privilege, the very prospect of experiencing one’s innate embodied vulnerability, may itself constitute intolerable suffering. For this class of persons, it appears that dependence is unthinkable, and vulnerability inconceivable. For example, data from Oregon confirms that “worries about loss of dignity and future losses of independence, quality of life, and self-care ability” were far more prevalent in motivating requests to die than were current issues of pain or symptom control.^{xii} A catastrophic illness or injury radically alters the course of a life built upon the assumption of physical independence. The necessity for any form of intimate care can be experienced as a violation of personal dignity. Similarly, impairments which

compromise self-management of one's bodily needs and functions may be experienced as shameful and degrading.

On the other hand, for persons with lifelong or long-standing physical or cognitive impairments, particular forms of vulnerability find their way into the mechanics of the daily life. They may remain unpleasant, and may challenge our sense of dignity and integrity, but their significance diminishes over the course of lives that permit us to flourish – in meaningful work, connection to community, pursuit of pleasure and relationship. Our embodied vulnerabilities become tolerable, because we have found resiliency where it is needed to preserve self-regard and meaning in life.

Where these two distinct life experiences and worldviews collide is where policy choices must be made regarding safeguards for physician-hastened death. On the one hand, it has been argued that providing unfettered access to those who find disablement undignified can simply be paired with safeguards to protect persons who do not share this view from being pressured to pursue a hastened death. This is a straightforward “individual choice” argument.

On the other hand, the assertion that such conditions as incontinence constitute an assault to dignity sufficiently grievous to warrant the pursuit of a hastened death is more than a simple expression of personal choice. The frequency and intonation with which the words “diaper” and “drool” are used by those who advocate for broad availability of assisted death upon request, should signal to us that certain iconic meanings are being invoked in support of these arguments.

Having to wear diapers and drooling are highly stigmatized departures from what is expected of adult bodies. Those of us who deviate from these norms experience social shame and stigma that erodes resilience and increases vulnerability. The more deeply these stigmatized accounts are embedded in our discourse and social policy, the more deeply virulent social prejudice takes hold within our culture.

To speak of diapers in a formal submission before a federal legislative committee, as did Dr. Derryck Smith on February 2^{xiii}, is no small matter of unconventional etiquette. The social and cultural forces that would embolden a person of professional stature and authority to speak of persons in vulnerable states with such contempt, demands that we reproach not the speaker, but the license we have given for insult and objectification.

To the extent that we embrace dignity and inclusion among our core constitutional values, we must attune our ears to consider how such speech may be heard by those who wear “adult diapers” while striving to flourish as human beings. Not only do such characterizations assault us to the core, but the recoiling they provoke both cheapens our lives and frays the fragile cords that link us to living worlds of community, whether we are at our prime or in our final days. To adults who wear diapers, it is not enough to say merely that they “are perfectly at liberty to choose to die how they wish”, as Dr. Smith concedes. What assurance can we offer that the physician who treats these adults at end-of-life will not stand at their bedside with horror – or revulsion – in his heart?

Of course there can be no such assurance. Already the cultural narrative that links diapers and drooling with worthlessness and degradation holds us firmly in its grip, and with each sanctioned utterance,

persons who have some degree of difficulty with swallowing and incontinence^{xiv} and persons who will need to confront such difficulties if they wish to live a little longer, are rendered more and more vulnerable, their claims to dignity and worth more and more precarious.

Moreover, the service of those who care for persons who may drool or wear diapers – many of whom themselves are members of socially vulnerable groups – is stigmatized and devalued as well. When Gillian Bennett took her own life in British Columbia in 2014 to escape the unfolding of her Alzheimer’s diagnosis, she wrote:

“I can live or vegetate for perhaps ten years in hospital at Canada's expense, costing anywhere from \$50,000 to \$75,000 per year. That is only the beginning of the damage. Nurses, who thought they were embarked on a career that had great meaning, find themselves perpetually changing my diapers and reporting on the physical changes of an empty husk. It is ludicrous, wasteful and unfair.”^{xv}

In its conceptual framework for strengthening health equity beyond narrow concentration on the immediate causes of disease, the UN Commission on Social Determinants of Health confirms that one of the “structural drivers” that make people vulnerable to poor health outcomes are “biases, norms and values within society”^{xvi}. It is for this reason, recognizing the profound cultural dimension of vulnerability, that deep reflection on the implications of eligibility criteria for physician-hastened death must go beyond an “individual choice” analysis to a broader contemplation of social impacts and potential harm to disadvantaged groups. To do otherwise overlooks the strong coercive powers of shame and stigma that can induce requests for hastened death.

Herein may lie one of the most compelling arguments for limiting access to physician-hastened death to circumstances of actual, rather than projected future suffering, as a measure to mitigate the cultural spread of stigma and prejudice against persons who are physically dependent. The dread of future shame cannot be a mode of suffering intended by the Court to warrant Charter intervention, whether that shame would derive from physical dependence, disgraceful conduct or financial ruin. Moreover, including definitional criteria requiring that “grievous and irremediable” medical condition be interpreted to mean “an advanced state of irreversible decline” would protect from inducement persons caught in the naked vulnerability of worthlessness and despair when confronted with grief, trauma, addiction and isolation – circumstances in which suicide prevention offers more robust protective capacity.

While there are compelling reasons in law and policy to recognize a limited right to physician-hastened death, there are equally compelling reasons, affirmed by the Court, to structure a carefully regulated framework of explicit safeguards. There is no single safeguard that will satisfactorily protect persons from heightened vulnerability, no single measure that will adequately bolster resilience to harm or inducement. Instead, a complex and subtle architecture for physician-hastened death will be required. Given the complex dynamics of vulnerability, suffering, resilience and flourishing, the blueprint for this framework must go beyond pure lines of simple black and white. There must be depth and substance to our approach, and a weight equal to the magnitude of a hastened death. No single physician, nor two

physician colleagues, however skilled and intentioned, can be presumed to bring to this process the layered understanding of a patient's experience of vulnerability required to ensure both robust protection and respectful support. The contributions of multidisciplinary clinical teams and other experts in medical and healthcare disciplines must be formally recognized for their role in broadening understanding of the context and circumstance for a request for hastened death. Most importantly, the assurance that no patient's death shall be hastened without their fully informed consent and without due consideration of alternative courses of action, including suicide prevention intervention where appropriate, requires some arms-length decision-making mechanism^{xvii} – neither so formal as to be burdensome nor so casual as to be meaningless. Written reasons provided by a decision-maker or decision-making body would contribute substantially to the development of a deep understanding of how physician-hastened death is delivered in a manner consistent with the principles of equality before and under the law.

Conclusion

What does it mean to protect the vulnerable? It is a phrase that is repeated with frequency through the Court's decision, and it has been spoken extensively throughout the six-month deliberations of the External Panel and the Joint Committee's deliberations. Protecting the vulnerable requires having laws that do not render us defenseless, policies that do not diminish our resiliency and social policy that shapes itself around a vision of promoting flourishing for all Canadians.

Parliament must now amend the Criminal Code to permit assisted dying, while at the same time restricting the exemption to protect against unlawful killing. The simplicity with which this task can be stated is crudely disproportionate to the challenge it now presents to Canadian legislators. On the one hand, we are obliged to protect vulnerable persons, but on the other hand, we may be required to consent to terminate lives in which vulnerability is too great to bear. On the one hand, we know that the experience of vulnerability is deeply rooted in social policy, as when needed supports and care are inadequately funded and inequitably distributed. Yet on the other hand, we must bear the agony of unfulfilled duty, when in the days and years to come, fellow citizens will choose to die because we have not done all that we could to support their living, because they could not – and should not have to – wait for those supports and care to which they were entitled.

We must bear this agony without numbing ourselves with rhetoric, without sacrificing our hallmark Canadian value of caring. We must perform our democratic and legislative responsibilities with prudence and care, accepting the inevitability of future litigation, as our Courts too must continue to shoulder the difficult burden of adjudicating whether persons situated differently from Gloria Taylor, persons who are not in advanced states of irreversible physical decline, can safely be included in an assisted dying regime.

More – much more – can be said about the delicate weave of vulnerability and resilience that shape the human experience. Much more as well can be said of flourishing as the ever-viable counterpoint to suffering. But for the purpose of its task, the distillation of two fundamental principles may help to guide the Committee's deliberations:

- As we build resilience, we do not extinguish vulnerability, but instead we restrain its power to divide us by deepening the suffering of some.
- As we promote flourishing, we do not eliminate suffering, but instead we immunize against despair as its natural endpoint.

All laws, all exercise of judicial and legislative power, whether they address the distributions of wealth, the allocations of care, or the protections of authority, must strive to build resilience and to promote flourishing. The legislative and regulatory implementation of the Supreme Court's decision in Carter should be no exception to this standard.

Endnotes

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- ⁱ Martha Fineman. 2008. "The Vulnerable Subject: Anchoring Equality in the Human Condition." *Yale Journal of Law and Feminism* 20 (1): 1–23.
- ⁱⁱ Testimony of Dr. Jeff Blackmer, Vice President of the Canadian Medical Association, before the Joint Committee on January 27, 2016. In his submission before the Committee, Dr. Blackmer emphasized the momentous significance of the introduction of a regime for physician-hastened death: "It must be recognized that this represents no less than a sea change for physicians in Canada."
- ⁱⁱⁱ As Roger Highfield puts it, Stephen Hawking is "a man who has defied the laws of medicine in order to rewrite the laws of physics". See <http://www.telegraph.co.uk/news/science/stephen-hawking/8989060/Stephen-Hawking-driven-by-a-cosmic-force-of-will.html>
- ^{iv} In the opening chapter to 'Terry Fox: His Story' by Leslie Scrivener, Fox reflects on his experience in the following terms: "I loved it. I enjoyed myself so much and that was what other people couldn't realize. They thought I was going through a nightmare running all day long. People thought I was going through hell. Maybe I was, partly, but still I was doing what I wanted to... It was an incredible feeling. The pain was there, but the pain didn't matter. But that's all a lot of people could see; they couldn't see the good that I was getting out of it myself."
- ^v In her essay titled "William Utermohlen - the Late Pictures" psychiatrist Patrice Polini observes "We witness here a relentless struggle by the artist to preserve his life through the creative process. To the extreme limits of his ability he has succeeded in preserving his world, to depict himself so as not to disappear.... The creative process allows a subject whose identificatory abilities are impaired, to maintain a sense of self and a sense of presence in the world." See <http://www.williamutermohlen.org/index.php/8-home-page/5-the-late-pictures-1990-2000>
- ^{vi} Personal communication with the woman's employer.
- ^{vii} On this point, the author notes the acknowledgment by Committee co-chair Senator Ogilvie on January 28, 2016, in his expression of thanks to the "remarkable Canadians" who had presented to the Committee that evening. While the sincere generosity of his words can be appreciated, it bears emphasis that what is perhaps most remarkable about the active democratic participation by people with disabilities such as Mr. Fletcher, Ms. Wiebe and Ms. Jarrett are the invisible arrangements of medical, personal and social support, both past and present, that have built their resilience and that work seamlessly to enable them to share their valuable perspectives.
- ^{viii} Zhi WI, Smith TJ. Early integration of palliative care into oncology: evidence, challenges and barriers. *Ann Palliat Med* 2015;4(3):122-131. doi: 10.3978/j.issn.2224-5820.2015.07.03
See also Temel Jennifer et al., Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *The New England Journal of Medicine*. Vol. 363:733-742. August 2010.
- ^{ix} Linda Ganzini, Elizabeth R. Goy and Steven K. Dobscha, Why Oregon Patients Request Assisted Death: Family Members' Views. *J Gen Intern Med*. 2008 Feb; 23(2): 154–157.
- ^x In the final report of the External Panel, results of an open online survey completed by nearly 13,000 Canadians indicated 72% of respondents favoured a national strategy on palliative care; 75% favoured a comprehensive national home care strategy and 75% favoured a national strategy on disability supports.
- ^{xi} See for example, CSDH (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization.
- ^{xii} Linda Ganzini, Elizabeth R. Goy and Steven K. Dobscha, Why Oregon Patients Request Assisted Death: Family Members' Views. *J Gen Intern Med*. 2008 Feb; 23(2): 154–157.

^{xiii} Testimony of Dr. Derryck Smith, Chair of the Physicians Advisory Council, Dying With Dignity Canada before the Joint Committee, February 2, 2016. In response to an invitation by Mr. Rankin, Dr. Smith described his experience of visiting "a number of people who were in the latter stages of dying from dementia". His description was graphic, in support of his argument that an assisted death should be authorized by advanced directive: "They are typically in bed, incontinent of feces and urine, in adult diapers 24-7. They do not know who they are or where they are. They cannot speak. This is not a condition most Canadians would want to be in at the end of their life. I certainly do not want to end my life that way.... I would challenge members of your committee to reflect on how they would like to die and what they would think about a relative of theirs dying in the sorry state of end-stage Alzheimer's and a year of living in a bed wearing an adult diaper. It's not sensible for people to be in that state at the end of their life."

^{xiv} The author includes herself in this category.

^{xv} Gillian Bennett, Dead at Noon, August 2014. <http://www.deadatnoon.com/page2.html>

^{xvi} CSDH (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization. P.42.

^{xvii} In various formulations, prior review and approval of physician-hastened death procedures were recommended to the External Panel to ensure that vulnerable persons are not induced to request an assisted death. Submissions to the Panel suggested that multidisciplinary members of healthcare teams and experts from relevant medical, palliative and psychiatric perspectives, as well as social workers and psychologists may be better positioned than individual physicians to make reliable determinations of the voluntariness of a request for assisted death. While the precise configuration of prior review processes differed in submissions heard by the Panel, each of these formulations involved assessment of a patient's vulnerability and possible sources of inducement as motivating factors in a request to die. The identification of alternate courses of action, such as treatments, supports and counseling, were often proposed as part of this prior assessment in order to minimize the risk of inducement and to ensure that requests were entirely voluntary and fully informed. See Consultations on Physician-Assisted Dying: Summary of Results and Key Findings, 2015, pp. 92-98.