

Reflections on Dignity, Disability and Dying

The following article was originally published on March 5, 2014 in the Montreal Gazette, prior to Quebec's Bill 52 being passed on June 5, 2014. This legislation - the first of its kind in Canada - allows for terminally ill Quebecers to request "medical aid in dying". This article is being published here with the kind permission of the author.



Bill 52's legislative limbo offers a time for reflection

By Catherine Frazee

With Quebec's Bill 52 now stuck in legislative limbo because of an imminent election call, perhaps there is time for us to listen closely to the overtones that are lingering from so much talk of "aid in dying."

Resonating darkly from the fading debate is one idea about dying - not the only idea, but one that has gripped us firmly. It is the idea of dying as relentless decline, a ruthless assault upon the selves we once were. In the

shadow of this idea, greater fear is provoked by dying than by death itself. Little wonder that "aid in dying" offers to forgo the dying process, advancing directly to death.

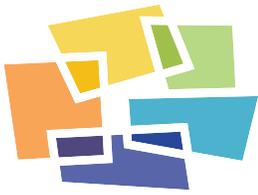
Perhaps we have chosen this particular idea about dying because of certain "habits of the heart" - certain reflexive assumptions about dignity and autonomy. And perhaps those convictions warrant an honest reconsideration.

Is human dignity truly bound up with the mechanics of personal hygiene? Or is dignity more about the intricate chemistry of how we are held in care and regard by those who stand near? Is autonomy really the blunt "carte blanche" of individual will? Or is it the pulsing engine of the warrior's heart, hell-bent on its defence of a vital, expressive, even if diminishing, self ?

The alternative idea of dignity and autonomy is what people with long-standing disabilities can be heard saying, if and when courts and media pause to listen.

The debilitations of disability, shame and stigma are layered like paint upon the canvases of our lives. Unlike the chorus of esteem that elevates certain embodied states, however frightful - birthing comes to mind - a drone of pity and repugnance compels a retreat from disability.

Yet Canadians with disabilities hold fast to an account of our lives as utterly dignified and richly interdependent. From the largest and most representative organizations giving political voice to disabled citizens and our families have come persistent and dire warnings that when we permit in the name of dignity the killing of some persons, we set in motion an irreversible unravelling of our delicate social fabric.



This caution - all but muffled by the trumpeting of an age of assisted death - must be accorded a fairer and more fulsome hearing. For as long as our moral impulses equate incapacity with indignity, there is no opening for a true embrace of disability. And if we cannot embrace disability, we will flee the disablements of dying by any means, invoking the language of rights to justify the termination of life.

Heaven help us if the most critical moral issue of our generation is to be decided on the footings of a thin logic of fear.

It is natural to fear dying, just as it is natural to fear birthing. Fear is not the problem. But when fear goes public, when the fear of one is taken up by the many, the result is a righteous denouncement of that which threatens us.

We have seen the cycle played out to a horrific end far too often.

We who inhabit bodies that cannot move, swallow, bathe or speak at will may or may not be individually endangered by formulations of “aid in dying,” such as those encoded in Quebec’s Bill 52. But regardless of our place in hierarchies of privilege, we will all, without fail, feel the blunt trauma of further denouncement.

Denouncement’s polar opposite is solidarity. When we choose to respond to dying with steady, compassionate attention, when we embrace the fearful but not the fear, we overcome our primal instincts of fight or flight. In this embrace of the frailties and the possibilities in ourselves, and in others, we rise to solidarity.

That is what we learned to do in relation to childbirth. Somehow, by the power of how we value and understand birthing, women find within themselves a conviction that trounces fear. Perhaps, just as we join with midwives in our embrace of birthing, we can join with palliative medicine to embrace dying in ways that engender courage, respect, even awe.

Along the way, we may find ourselves ready for a radical reimagining of equality that better accords with the fragility of embodied human life.

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Suggested readings and videos:

The Fifth Estate (2012) <http://www.cbc.ca/fifth/episodes/2012-2013/the-life-and-death-of-gloria-taylor>

Background Paper: Euthanasia and Assisted Suicide in Canada <http://www.parl.gc.ca/Content/LOP/ResearchPublications/2010-68-e.pdf>

Recent end-of-life related Canadian cases <http://hospitalnews.com/a-life-or-death-decision/>

NSHEN video - Jocelyn Downie: The right to die <http://www.nshen.ca/index.php?id=191>

NSHEN video - Ethics and palliative care <http://www.nshen.ca/index.php?id=186>

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We hope you have found our communication helpful and informative and would like to continue providing these to you.

NSHEN: Upcoming Events...

October 22-23, 2014 - NSHEN Annual Conference - Risky Business: Ethics of Risk in Health Care

The 2014 NSHEN Annual Conference will take place on October 22-23, 2014 at the Best Western in Liverpool, NS. The conference will explore ethics of risk in health care, including sessions on mental health, cultural safety, public health, duty to care, and disclosure of adverse events. We are excited to announce that Dr. Peter Vaughan, Nova Scotia's Deputy Minister of Health and Wellness, will give the keynote address on risk at the provincial health system level.

Online registration will open and more information will be posted on NSHEN's website in the coming weeks. You may also email krista.mleczkoskerry@iwk.nshealth.ca for more information.ence when registration opens, please email

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- * Our strategic goals are collectively established by the collaborating partners
- * NSHEN involves academia, government, and health care organizations in a single network

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