

Does the right to life entail a right to die? *Le droit à la vie implique-t-il le droit de mourir?*  
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## **Introduction**

I thank the organizers for hosting this important and timely discussion on the dignity of life and for inviting me to share some perspectives on this issue. I speak from the perspective of a family physician who cares for people with intellectual and developmental disabilities and as an ethicist. I served on the Ethics Committees of the Canadian Medical Association, the Canadian College of Physicians and Surgeons of Canada, and the College of Family Physicians of Canada during a time when these organizations were reviewing their policies on euthanasia and assisted suicide (EAS). I am concerned about the negative ramifications of laws permitting EAS for people with disabilities and for the profession of medicine, especially palliative care.

The UDHR was adopted in the aftermath of the violence of World War II and awareness of the extermination of people deemed to be “unfit” and unworthy to live. It reflects a global consensus that such disregard for human lives ought never to recur. The UDHR recognizes that the right to life of all members of the human family is the basis of all other human rights and that every life has inherent and equal worth. In this presentation, I urge member States of the United Nations to affirm this framework of the UDHR against more recent and, I argue, dialectically opposed frameworks for understanding and applying to public policy the fundamental human right to life. This could entail new ways in future UN documents to articulate the inherent dignity and worth of every human life to avoid ambiguity arising from the use of terms like “dignity”, “worth”, and “life” by proponents of EAS. It will entail that States:

- develop competencies to assess rigorously claims that death by EAS is a human right, including the philosophical and ethical assumptions supporting those claims;
- sponsor investigation into empirical questions relevant to EAS;
- develop, monitor and manage regulatory regimes that promote and protect the fundamental right to life of all citizens, especially people with disabilities and other groups made vulnerable by laws permitting EAS;
- support, as an appropriate and necessary extension of the human right to life, the right to good palliative care of any who are in need of it.

## **PART A: Is there a right to die?**

In June 2016, Canada became one of a handful of countries that have passed a law permitting EAS under certain conditions. One argument that prevailed to make this law possible is the claim that the “right to life” entails a “right to die”.

The “right to life” is declared in section 7 of the Canadian Charter of Rights and Freedoms (CCRF, 1982). This Charter itself is framed by the “right to life” declared in the Universal Declaration on Human Rights (UDHR, 1948). In my chapter in the booklet being launched today, I argue that the recent trend to frame the fundamental human right to life in the UDHR to include a so-called “right to die” is flawed, because they are dialectically opposed concepts.

The example of what happened in Canada highlights the importance, ethically, of paying attention to how human rights are framed and understood, and how mis-framing can result in changes in law and social practices.

Another example of this shift in framing is the 2018 Comment No. 36 on article 6 of the International Covenant on Civil and Political Rights, on the right to life. While this document does not advance a position on EAS, it concedes that some member states have laws permitting these practices and accepts tacitly that these laws are compatible with upholding the right to life, as long as there are some safeguards in place for vulnerable groups.

In my chapter, I unpack the claim that one has a “right to die” by showing that it contains several distinct claims:

- persons have a right to die when and how they wish;
- exercising this right requires the State to mandate some citizens, usually healthcare professionals, deliberately to assist in ending the lives of other citizens;
- being dead is a state of non-being, and this state of non-being is better than life with a disability.

The first claim that persons have a right to die when and how they wish assumes that persons are entitled to regard their lives in the same way as their property. In Canada, this view was expressed by Sue Rodriguez, a young woman with a neuro-degenerative condition called ALS, to the Canadian parliament and later, the Supreme Court of Canada: “If I cannot give consent to my own death, whose body is this? Who owns my life?”

One pertinent ethical consideration overlooked by Sue Rodriguez’s question, who owns my life, is whether human life is the sort of thing that any human being can “own”. Such a view presupposes that a life is worth only as much as the individual living it attributes to it, an object whose owners are at liberty to control, use, and discard as they wish. This is not the notion of life that underlies the right to life in the UDHR which holds that human life has inherent and equal worth for all human beings.

Another assumption that proponents of the alleged “right to die” have is that the State is required to mandate some citizens deliberately to assist in ending the lives of other citizens. If states require health care professionals who oppose EAS on medical, philosophical, ethical, or religious grounds to undertake or be complicit in these practices, this would involve a contravention of Article 18 of the UDHR. This Article declares that everyone has the right to freedom of thought, conscience, and religion. In Ontario, this has happened through an Ontario court’s ruling that it is a justified violation of the right to freedom of conscience to require all physicians in that

province of Canada to make an effective referral for euthanasia even if they oppose this on moral grounds, or risk losing their license to practise. Moreover, the effects of permissive laws on EAS on the medical profession, especially palliative care, has been divisive. Many palliative care physicians and patients have found it confusing and distressing that an area of medicine that upholds ethical limits consistent with the right to life has now had these limits eliminated by legislation supporting EAS.

A third assumption that proponents of the alleged “right to die” make is that under certain conditions, “being dead” is better than “being alive”, especially when such a life involves current or anticipated disabilities and adversities that the person finds intolerable to cope with. What is often overlooked in this claim is the assumption that the state of “being dead” equals the state of “non-being”. This assumes a materialist notion of reality and a means-ends approach to moral reasoning in which any means to relieve suffering is ethically justified. There is no reason, however, why *a priori* these should be held to be universally accepted principles or the basis of public policy. For instance, the view that being dead equals non-being is uncertain. It is also not obvious that the only means to relieve suffering is to end the life of a person.

More gravely, the position that it is better to be dead than to live with a disability assumes that such attributions of worth are strictly personal and do not have implications for the worth of the lives of those coping with similar disabilities and adversities. I am not downplaying the challenges faced by persons with disabilities. As a physician who has a practice that supports such persons, I am aware of these challenges and the suffering that can arise because of them. I am, however, concerned that, if public policy validates the principle that it is better to be dead than to live a disability, there will be less emphasis placed in health care and in society on helping to support people with disabilities and enabling them to accept and cope with their disabilities through good care, and more fear and negative attitudes regarding a life with disability. “Being dead than disabled” reinforces the view that life with a disability is worth less than life without one. It is contrary to the spirit of the UDHR and the UN Convention of Rights of Persons with Disabilities, both of which hold that every human life has inherent and equal worth.

Some have argued that the positive obligation of the state is justified to bring an end to what persons regard as intolerable suffering caused by their illness or disability, and moreover, that the lack of state intervention to terminate such a person’s life based on her or his request amounts to the state extending, and thus contributing, to that person’s suffering. However, such arguments overlook the reality that it is the healthcare system, economic, social and other circumstances (e.g., lack of needed support, lack of proactive interventions to address a person’s isolation, poverty, and lack of control over their lives) that are, to a large extent, causing such adversities and suffering. The state’s intervention to terminate a life on the basis of a “right to die” signals the failure of its positive obligation to ensure conditions necessary for protecting the right to life and promoting its flourishing in people who are coping with the transition to experiencing disability in their lives, which takes time and supports.

Even with safeguards, laws that permit EAS under certain conditions are, in practice, often insufficient to deal with the complexities of assessing decision-making capacity or suffering of many people with disabilities. The state's obligation under the UDHR to protect the right to life of these vulnerable persons is often not observed. For instance, a recent review of Dutch cases of death by euthanasia of 9 persons with a diagnosis of intellectual disability and/or autism found a lack of due diligence on the part of physicians who assessed them for eligibility for euthanasia. In many cases, physicians assumed intolerable or irremediable suffering on the basis of persons having an intellectual disability or autism alone, or did not explore alternative courses of action to euthanasia to address suffering or involve any family members of the person.

Where states are also the funder and provider of healthcare services, there can even be a conflict of interest in laws recognizing a "right to die" by EAS. Studies have shown that death by EAS represents considerable savings over years of costly care and support for people with chronic illnesses and disabilities.

From the ethical analysis, above, I propose that there are some important implications for member States of the United Nations in developing competences to uphold the right to life and other fundamental human rights in the UDHR.

To reiterate, with some suggestions of helpful resources, states should:

- develop competencies to assess rigorously claims that death by EAS is a human right, including the philosophical and ethical assumptions supporting those claims. Those in public policy can draw on the work of scholarly groups already engaged in reflection and research that is informed by an understanding of the inherent and equal worth of every human being, which is shared by the framework of the UDHR. For example, the International Association of Catholic Bioethics (<https://www.iacb.ca/statements/>) and the Pontifical Academy for Life (<http://www.academyforlife.va/content/pav/en.html>).
- sponsor investigation into empirical questions relevant to EAS; such as the effect of EAS on families; on healthcare professionals providing palliative and other forms of care; social and economic factors that are contributing to requests for EAS that states can and should address.
- develop, monitor and manage regulatory regimes that promote and protect the fundamental right to life of all citizens, especially people with disabilities and other groups made vulnerable by laws permitting EAS; [E.g., the Vulnerable Persons Standard for public policy developed in Canada.]
- support, as an appropriate and necessary extension of the human right to life, the right to good palliative care of any who are in need of it. [See the 2008 Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights of the

International Association of Hospice and Palliative Care and the Worldwide Palliative Care Alliance.]

In conclusion, the right to life as framed in the UDHR is not consistent with an alleged to die by EAS. It is my hope that states who are signatories of the UDHR on its seventieth anniversary may continue to affirm this distinction.

Thank you.