



# Collaboration and research imperatives for a growing right-to-die movement

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## Abstract

This commentary discusses key controversies surrounding assisted dying that have now evolved, creating further tensions and divisions among assisted dying organizations, adding to existing controversy based on ethical, political, and theological grounds—all shaping public health policy in Canada and elsewhere. The growing worldwide trend in the right-to-die movement is increasingly focusing on medical assistance in dying (MAID) with most service organizations (societies) devoted to a sanctioned, legislatively prescribed approach. While in consequence important changes have occurred in numerous countries and jurisdictions with successful challenges on the absolute prohibition to assisted dying, it is arguably the case that as many—if not more—people are still denied this controversial right to have a peaceful, reliable, and painless end of their own choosing. We examine implications of this for beneficiaries and service providers, while showing how a collaborative and strategic approach that includes all options to access a human right to determine our own end-of-life options can effectively address these tensions for the benefit of all right-to-die organizations, regardless of differences in their respective tasks, directions, and agendas, with each mutually reinforcing the work of the other. We conclude by stressing the essential need for collaboration in terms of furthering research to better understand challenges facing policymakers and beneficiaries and potential liabilities for health professionals providing this service.

## Résumé

Ce commentaire traite des principales controverses entourant l'aide à mourir qui ont maintenant évolué, créant de nouvelles tensions et divisions parmi les organisations d'aide médicale à mourir, ajoutant à la controverse existante fondée sur des motifs éthiques, politiques et théologiques—tous façonnant la politique de santé publique au Canada et ailleurs. La tendance mondiale croissante du mouvement pour le droit de mourir se concentre de plus en plus sur l'aide médicale à mourir (AMM), la plupart des organisations de services (sociétés) se consacrant à une approche sanctionnée et prescrite par la loi. Alors qu'en conséquence des changements importants se sont produits dans de nombreux pays et juridictions qui ont contesté avec succès l'interdiction absolue de l'aide à mourir, il est sans doute vrai qu'autant de personnes—sinon plus—se voient encore refuser ce droit controversé d'avoir un accès paisible, fiable et indolore fin de leur propre choix. Nous examinons les implications de cela pour les bénéficiaires et les prestataires de services, tout en expliquant comment une approche collaborative et stratégique qui inclut toutes les options pour accéder à un droit humain afin de déterminer nos propres options de fin de vie peut résoudre efficacement ces tensions au profit de toutes organisations à terme, quelles que soient les différences dans leurs tâches, orientations et programmes respectifs, chacune renforçant mutuellement le travail de l'autre. Nous concluons en soulignant le besoin essentiel de collaboration en termes de recherche supplémentaire pour mieux comprendre les défis auxquels sont confrontés les décideurs politiques et les bénéficiaires et les responsabilités potentielles des professionnels de la santé fournissant ce service.

**Keywords** Assisted dying · Suicide · Healthcare policy · Strategic organizing

**Mots-clés** Aide médicale à mourir · suicide · politique des soins de santé · organisation stratégique

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Allowing voluntary assisted dying (VAD) has emerged as a matter of public health wherever it has been proposed. In Canada, the milestone Supreme Court decision in 2015 considered the question on the basis of life, liberty, and the security of the person, and the right not to be deprived thereof as enshrined in the Constitution. The trial judge carefully weighed public health considerations with the creation of an assisted dying regime that would both prevent its abuse, protect the vulnerable, and offer persons relief from intolerable suffering (*Carter vs Canada, Attorney General, Supreme Court Judgments, 2015*).

The worldwide right-to-die movement has greatly evolved since 1975 when Derek Humphry helped his wife who was dying from breast cancer to take her own life which in turn led to the founding of the Hemlock Society five years later. The ethical foundation for assisted dying then, as now, was grounded in a human right that persons should be allowed freely to determine when, where, and how they want to die. Yet the very notion of assistance in dying has also become increasingly contested, opposed by detractors on numerous grounds, with controversy even finding its way into right-to-die organizations themselves.

A review of the past decade will reveal tension within this worldwide movement between those who advance the prevailing development of medically assisted dying (MAID) that is evolving through a legislated regime which identifies how the very process may be implemented, and others who insist on not limiting the ways to a peaceful, reliable, and rational death exclusively through legislation. The different controversies are also identified in recent press reports (e.g., *N.Y. Times, Der Spiegel*) and a Wikipedia entry about the World Federation of Right to Die Societies (WFRtDS) that gathers such organizations globally and held its most recent bi-annual conference in Toronto in November 2022 (*World Federation of Right to Die Societies, 2022*).

What light then can we shed on this challenge for those involved in this movement, and what are the policy options for them? If we accept that the state of healthcare provisions promote suicide ideation and suicidal acts, then it may also be the case, as Katie Engelhart mentions in a quotation from her book, *The Inevitable: Dispatches On The Right To Die* (Engelhart, 2021), that our best hope for medical assistance in dying is most persuasively advanced in those countries that have an efficient, national healthcare system, universal and accessible to all. Why? Because it is a better buffer to so-called slippery slope arguments that MAID encourages suicide unless there is adequate support for the poor and disabled who might otherwise ostensibly “give up” and attempt suicide as an escape from their current misery. If that seems a plausible or persuasive argument, then advocates of a right-to-die movement might consider the following in identifying strategies to advance a human right to die.

With the MAID approach to reliable, peaceful, and painless dying, it means arguing that it is inhumane and illogical to prolong the suffering of some who seek this service but are denied it because others are also suffering for a lack of adequate services such as better palliative care, better health services, adequate housing, and even adequate income to put food on the table. That very opposition to MAID has already been advanced by some disability groups even if, on the face of it, seemingly untenable and unfair. It is also important to consider that allowing for voluntary assisted dying does not necessarily support or endorse the act itself.

That said, what about persons still not eligible for MAID or persons choosing not to medicalize their final act by involving doctors and other professionals? What if a person doesn't want strangers to be a part in this very personal final act, doesn't want to be sick, suffer intolerably to qualify for assistance, and have to face a prolonged period of waiting as is the case currently even under Canada's newly revised legislation, Bill C-7? Are we not imposing treatment against a person's will by prohibiting any other course to a peaceful, reliable, and painless death? To what extent are we prepared to support the call for patient-directed practice as opposed to doctor-directed interventions regarding end-of-life options, to shift a focus away from suffering towards one of autonomy of the person?

Societies or organizations focusing on a medical (MAID) path to achieve this right have expressed concerns and even opposition to others advocating for all options, unrestricted by state or medical regulation. But if MAID is unsuccessful, shouldn't options be offered in the way of referrals and support to other responsible resources without fear it will necessarily detract from wider MAID acceptance? Is that even possible? If one's regional or national MAID society is finding MAID applicants being widely refused, what then should become of them? Do we simply forget or drop them from our agendas? Isn't doing so unethical, irresponsible, and a contradiction to that expressed movement-wide position that this regards a fundamental human right to be denied no one? While it is obvious that medically assisted dying necessarily involves medical and state regulation and oversight, is this a justification to prohibit all other assisted dying not calling on professional intervention regulated by legislation?

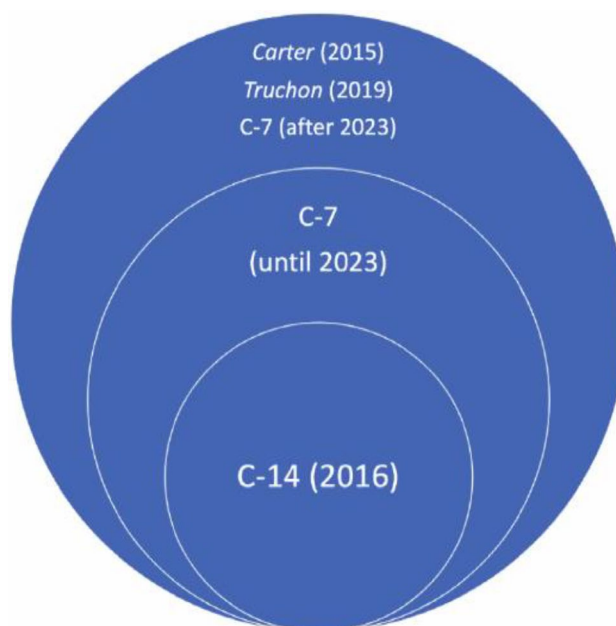
Some argue that everyone should at the very least be informed about other supports, methods, and resources that may be available for them. Responsible resources and information are available. Better collaboration would include referrals as well between organizations with different agendas, including mutual support in advocacy even if advancing differing agendas. That would then be in line with the avowed philosophy that all are advocating a human right for everyone whether going a legislated medical or

an optional route. If a person contacts a society that focuses on self-deliverance, rational do-it-yourself methods such as stopping eating and drinking (VSED), or other voluntary assisted dying (VAD), and is open to MAID that exists in that person's jurisdiction, then she or he should be referred there as well of course. This is why, for example, the Canadian chapter of Exit International and Right to Die Society of Canada have referred to the MAID-focused organization, Dying With Dignity Canada. Such reciprocal relationships between different organizations would strengthen the wider movement. It could also help individuals not MAID-eligible so they wouldn't simply be sentenced to die alone, uninformed about how family and friends might safely and legally be with them, for example. Circling the wagons by some right-to-die organizations in a self-protective way that is not inclusive of everyone else can easily backfire and render the entire movement considerably weaker.

From an organizing perspective, it's important to fully appreciate how working collaboratively can advance all right-to-die societies jointly. Opponents of MAID have shown themselves to become increasingly vocal and powerful whenever MAID criteria are proposed for greater inclusion. In Canada, we experienced this in a forward, then backward direction as MAID criteria were challenged. The original Carter decision in 2015 set fewer limits on access than successive legislation. Dr. Jocelyn Downie in a recent presentation illustrated this with a graph showing the wider access circle vs the more restrictive, from the first Carter decision to Bill C-14, a movement from its successful Quebec challenge in the Trouchon case in 2019, to the present legislation under Bill C-7 with the anticipated additional widening of access to MAID in 2024 (Fig. 1).

On the one hand, societies working to achieve MAID services in their respective jurisdictions may reasonably fear others advancing a right-to-die beyond legislated boundaries defined by medico-legal authority. Any associations they might have with those other societies could be felt to be a liability detracting from potential public and governmental support with program funding for legislated assisted dying. In other words, public opposition to the entire idea of assisted dying might increase inasmuch as that allegedly invites or promotes unwanted suicide, especially in places where health and social welfare supports are lacking or unaffordable.

On the other hand, it's arguably also the case that societies advancing the right to die without medical or other formal sanction (AKA the "non-sickness model") can actually serve to justify and bolster the need to advance legislated regulation of this practice, thereby strengthening organizations working for MAID. Offering persons a sanction-free option to painless, reliable dying reinforces a perceived need to control the practice, especially with the increasing technology



**Fig. 1** Successive MAID access in Canada from Carter (2015) to Trouchon (2019) and anticipated 2024 widening of legislated medical regime (credit: Dr. Jocelyn Downie)

around methods and new knowledge that continues to evolve making it all more accessible. It's not far-fetched to see how some right-to-die opponents will turn to support organizations working uniquely within a legislated, medical regime as non-sanctioned alternatives become known, more accessible, and raise corresponding alarm. Recent surveys in Canada indicated 33% to be "enthusiastic" supporters of MAID while 48% indicated "cautious" support for it (Pennings, 2020).

Advances for MAID eligibility promoted by organizations such as Canada's Dying With Dignity can also be seen to further the underlying project that dying when, where, and how with dignity is, in essence, a fundamental human right. In this respect, even if their work is limited in focus, it's a win-win situation, each organization with different agendas and tasks fortifying the other. The more acceptance for MAID, the more it moves the project of assisted dying into a wider population with increased conversation and growing normalization. Working together, organizations can best effectively counter opposition by simply denying any and all assisted dying services, an all-too-easy argument made compelling, however, in a simplified, binary presentation of a complex issue.

Collective strength in this movement can in fact partly lie in pointing out how such work helps to discourage a public health concern regarding irrational, impulsive suicide. Without MAID or informed, rational-based alternatives to ending one's life, one simply drives people to attempt irrational, impulsive, and desperate acts that may likely endanger others and will surely result in trauma for friends, family, and first responders.

There exist many such accounts in coroners' reports in Canada as elsewhere. Paradoxically, societies can work jointly with suicide prevention initiatives.

Last but not least importantly, increased collaboration among all right-to-die organizations facilitates a great need for sociological, legal, health, and psychological research on assisted dying. It's only through such collaboration that one is able to establish what criteria are set out for self-deliverance by organizations or self-help groups, why persons turn to them for their help, their need as viable voluntary dying options, and how and why persons were excluded from MAID where those services are currently offered. Ongoing studies will clarify and establish further to what extent doctors and others involved in facilitating and administering MAID can legally do so without risking malpractice lawsuits for denying the service, or prosecution for crossing some line and approving the procedure in the first place.

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