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Expertise:

#bioethics
#human rights
#euthanasia
#assisted suicide
#palliative care
#Canada

» **Trudeau project:** Building communities of engagement on end of life law, policy, and practice

Project objectives: To build communities of experts in multiple disciplines and sectors and marshal their efforts in four areas that require urgent attention:

1. palliative care (by facilitating mutual understanding and fostering progress in the law and in policy directions);
 2. advance directives (by improving education);
 3. withdrawing and withholding treatment that may keep the patient alive (by fostering progress in the law and in policy directions);
 4. voluntary euthanasia and assisted suicide (by gathering data and facilitating mutual understanding).
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My project starts with the assumption that we are all committed to building a Canada that cares deeply and effectively for the dying. A Canada that doesn't accept people dying in pain. A Canada that doesn't accept people trapped in bodies that only support lives that, for them, no longer have meaning. A Canada that says "we can, and must, do better."

So, assuming we all share that commitment, how do we get there? More specifically, how would I, as a Trudeau Fellow, hope to contribute to us getting there?

There are four main areas of end of life law, policy, and practice that require the most urgent attention: palliative care; advance directives; unilateral withholding and withdrawal of potentially life-sustaining treatment; and assisted death. Until we resolve the problems in these areas, Canadians will continue to suffer at the end of life. There are also four activities that must be undertaken to resolve these problems: building shared understanding; gathering data; advancing law and policy reform; and enhancing education. I believe that a central reason why we have failed to make sufficient progress in relation to these areas of concern and activities is that experts are operating in silos and groups are locked into corrosively oppositional dynamics. We need the resources (human and financial) and deliberate intention to bring people together. Through the Trudeau Fellowship, I propose to build communities of engagement around these activities through specific projects on the areas of particular concern. These communities will produce concrete results with respect to their particular issues but they will also build relationships and practices of engagement that will last beyond the Fellowship and be available for future initiatives. They will serve as a model for effective strategy for resolving difficult public policy issues. I believe that through this project, by bringing together multidisciplinary and multisectoral teams with the object of concrete advancement of law, policy, and practice, we will be able to make a tangible difference in this complex, historically contentious, and seemingly intractable area which is in its every fibre about human rights and dignity.

Palliative care (shared understanding, law and policy reform)

We have much to be proud of in terms of palliative care in Canada. We have some tremendous providers, programs, services, and units. We are witnessing improvements in access and quality that are impressive. However, the inexcusable bottom line is that a significant, intolerable, number of people who could benefit from palliative care services have no access to them. Far too many people are suffering unnecessarily as they die. We need more funding for palliative care services, more palliative care education of health care professionals, and structural changes in our health care system (e.g., permitting and facilitating the provision of services beyond the boundaries of a terminal diagnosis and the walls of hospitals).

Historically, there has been a gulf between the palliative care community and many of those who support decriminalization of assisted death. But bridges can be built. More advocates of decriminalization are seeing the need to work towards increased funding for palliative care and better palliative care education in medical and nursing schools. More palliative care providers are taking the position that palliative care and assisted death are complementary rather than mutually exclusive. As someone who has long argued for both decriminalization and palliative care services and education, I will host a meeting to bring together leaders in these historically-divided communities to build shared understanding – to express concerns and exchange information and ideas, particularly for future collaborations.

In addition, there is one specific palliative intervention that is trapped in legal uncertainty and clinical irregularity – terminal sedation, which is deep and continuous sedation combined with the withholding or cessation of artificial hydration and nutrition. Each element (sedation and withholding or withdrawing of hydration and nutrition) is independently legal. The question is whether they remain legal when combined. That is, if I am imminently dying (i.e., in the next few days), then to stop hydration and nutrition won't shorten my life or cause my death. Terminal sedation in that context seems uncontroversial. But imagine a situation in which I am diagnosed with ALS (a lethal degenerative neurological disorder). I live with it for some while but, perhaps six months before dying, I ask to be deeply sedated, thereby creating the need for artificial hydration and nutrition. I then refuse all artificial hydration and nutrition. The cause of my death would be the lack of hydration and nutrition. Is this allowed? There is, perhaps surprisingly, no law directly on point. Indeed, the most that Justice Smith could say on this in *Carter v. Canada* was “So far as I am aware, palliative or terminal sedation has not been the subject of judicial consideration in Canada. It seems, however, to be a practice that may fall within the principles already described with regard to informed consent and potentially life-shortening symptom relief.” Unfortunately, that “it seems” that something “may” fall within established principles leaves health care providers in the shadow of potential liability and leaves patients without the foundation for a demand for access. Both the practice and policies around terminal sedation are uneven. A patient may or may not receive it – because of a lack of clinical competence or because of a difference of opinion between the patient and his or her doctor or health care institution about the legality or morality of the practice. The confusion regarding this practice results in unnecessary suffering.

I will bring together a small team of academics and practitioners from law, ethics, palliative care, and critical care for an intensive law and policy reform workshop. Each will have prepared a background report based on their disciplinary expertise (e.g., a thorough review and analysis of the ethics, law, and existing guidelines with respect to this practice and data with respect to its actual practice). Together, they will develop arguments for law reform to ensure that the law on the issue is consistent with the Charter and the fundamental values of Canadian society and that the law, reflecting the bounds of ethics, permits clinical interventions that best minimize suffering. From there, clinical practice guidelines can be developed to ensure that practice follows the law and education programs can be developed to ensure that the guidelines are followed.

Advance directives (education)

Advance directives (also known as “living wills” or “durable powers of attorney for health care”) are now legally binding across Canada. We can, through advance directives, ensure that our wishes about end of life care are followed even

when we can no longer speak for ourselves. The problem with respect to advance directives is not the law but rather the implementation. Far too few people have completed legally valid and clinically useful advance directives. So even though there is a way for people to get their wishes followed, there often isn't a will.

Public education is an important tool for responding to the problem of insufficient uptake, legality, and clinical utility. However, others are better situated than I am to develop public education modules on advance directives. And, indeed, a number of useful resources have been developed recently and should be promoted. There remains, however, a real need for education on advance directives for health care professionals and lawyers. I will bring together a team of legal academics, clinicians, and members of the public to develop educational modules for health care professionals and legal professionals. It is important for health care professionals to better understand the legal status of advance directives so that they can offer more informed assistance when patients consult them on completing directives and, as well, so that they can better understand what they are legally obliged to do (or refrain from doing) when presented with a patient's advance directive. The team will produce an online module for medical students and residents that can be included in a suite of online Health Law modules I am already co-producing with a colleague at the Dalhousie Health Law Institute. As the people often asked to assist individuals with their advance directives, it is also important for lawyers to better understand the health context within which advance directives operate. To that end, the team will prepare and share a set of materials that will be made available to faculty at law schools across Canada interested in teaching about advance directives in courses such as Health Law or Wills and Estates and faculty interested in establishing an Advance Directive Clinic to be offered in the community.

Withholding and withdrawal of potentially life-sustaining treatment (law and policy reform)

Fortunately, we have left in the past the practice of keeping people alive against their express wishes. If I am ventilator-dependent and paralyzed in bed, my request to remove the ventilator must be respected. But what if I have sustained a traumatic brain injury and my family want treatment continued while the health care team have decided that treatment would be "futile"? Or what if I have advanced cancer and want all interventions for a long enough window to see whether some traditional medicines might work but the doctors want to put a Do Not Resuscitate Order on my chart? In Ontario, thanks to the Supreme Court of Canada decision in *Cuthbertson v. Rasouli*, the answers to these cases are somewhat clear. But the rest of us are mired in a controversial and corrosive state of confusion. We need provincial legislatures to step up and clarify the law and establish tribunals for the resolution of conflicts.

I will bring together a team of individuals from (at a minimum) law, ethics, medicine, nursing, and health administration for another intensive law and policy reform workshop. The team will be challenged to draft a proposal addressed to provincial/territorial governments for a statutory regime and institutional structure with the expertise and authority needed to resolve otherwise intractable conflicts with respect to withholding and withdrawal of treatment in a fair and efficient manner. This team will also draft template institutional policies with respect to resolving conflicts about withholding and withdrawal of potentially life-sustaining treatment to either complement the legislative initiatives if successful or to fill the gap if unsuccessful.

Voluntary euthanasia and assisted suicide (data gathering, shared understanding)

Voluntary euthanasia and assisted suicide are clearly illegal in Canada. Both are prohibited under the Criminal Code. And yet this is all about to change. Within the past twelve months, the Supreme Court of Canada struck down the Criminal Code prohibitions on assisted death, a bill to decriminalize assisted death was introduced in the Federal Parliament, and legislation to permit medical aid in dying was passed by the Quebec National Assembly.

Quite simply, it is impossible to predict precisely what work will need to be done over the term of the Trudeau Fellowship in this domain. Obviously, the next steps will vary dramatically depending on what steps various key players decide to take in response to the Supreme Court of Canada decision. In particular, what federal, provincial, and territorial governments will do (if anything). However, there is no doubt that two things are needed: data on end of life decision-making; and engagement with the public and policy-makers. First, we have, in Canada, no reliable data on the

incidence or prevalence of the various kinds of end of life decision-making. For example, how many people die as a result of terminal sedation? Voluntary stopping of eating and drinking? Life-ending acts without the explicit request of the patient? Assisted suicide? Voluntary euthanasia? It is essential for sound public policy, that we have that data. I will bring together a team of empirical researchers from Canada, the Netherlands, Belgium, Australia, and New Zealand to design an empirical study that will enable us to gather the data we need in Canada to track these practices over time and across jurisdictions (the Fellowship will enable the protocol and grant applications to be written – the study itself would be funded through other sources). The lead end of life decision-making researchers in these countries have already agreed to be a part of this team. Second, we have a deficit of understanding of the issues amongst politicians and the public. To contribute to shared understanding, I will build upon my previous work in these two arenas. I will expand my website by establishing sister sites in the countries from which the members of the teams outlined above come (www.eol.law.dal.ca), speak in the community (from high school classrooms to church basements), and speak through the traditional media and social media. I will also organize a series of sessions with federal, provincial, and territorial parliamentarians across Canada modeled on the Bacon and Eggheads series run by the Partnership Group for Science and Engineering (www.pagse.org/en/breakfasts.htm).

Bringing it all together

In sum, as a Trudeau Fellow, I will engage in a deliberate process of building community engagement across disciplines, sectors, and countries focusing on the above four areas of end of life decision-making. Many of our past failures in advancing respect for human rights in the domain of end of life care are a result of silos of expertise and deep divides across moral positions. I will therefore build teams (with overlapping membership as appropriate) to participate in the four activities: facilitating shared understanding; gathering data; advancing law and policy reform; and enhancing education. This approach will advance our understanding and capacity to address the most pressing issues in end of life law, policy, and practice today and in the end contribute to us getting to a Canada that doesn't accept people dying in pain. A Canada that doesn't accept people trapped in bodies that only support lives that, for them, are no longer worth living. A Canada that cares deeply and effectively for the dying.