



Joint Centre for Bioethics  
UNIVERSITY OF TORONTO

## JCB Discussion Paper

# An Ethics-based Analysis and Recommendations for Implementing Physician-Assisted Dying in Canada

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## BACKGROUND

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On February 6, 2015 the Supreme Court of Canada (SCC) issued its unanimous *Carter*<sup>1</sup> decision to strike down sections 241 (b) and 14 of the Canadian *Criminal Code*<sup>2</sup> insofar as they prohibit ***physician-assisted dying*** (PAD), (terms in boldface italics are defined in Appendix I) but suspended the decision for one year to allow for a regulatory response. That deadline was extended by four months to June 6, 2016 after an application to the SCC by the Attorney General in January 2016.<sup>3</sup> If a regulatory response is not implemented by that date, the SCC ruling parameters will provide the only guidance. The SCC *Carter* decision outlined that PAD will be permissible for competent adults if the following conditions can be met: “(1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.”<sup>1</sup> The ruling comes at a time when Canadian public opinion suggests robust support for this ruling with approximately 80% of the public in favour of allowing access to PAD.<sup>4,5</sup> Support among the healthcare community has been variable, with many looking for regulation, processes and safeguards.<sup>6</sup>

Establishing an accountable process that respects an individual’s autonomous decision, prevents harm to ***vulnerable*** populations and supports healthcare professionals is required. On an individual level, the response to a request for PAD must be compassionate, ***patient*** focused and skilled. Although we can learn from the experience of other jurisdictions with PAD, Canada will ultimately require a process that reflects its values, population demographics, geography, as well as legal and healthcare systems.

## PURPOSE

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This paper seeks to articulate the broad ethical dimensions and implications of implementing PAD and to provide ethics-based recommendations to inform the development of PAD policy and supporting practices. We identify six overarching substantive and procedural ethical principles that guide our recommendations: accountability, collaboration, dignity, equity, respect and transparency. This paper is intended to provide ethics-based guidance for a wide range of stakeholders including: legislators, policy makers, healthcare professional bodies and associations, organizations and healthcare providers (HCPs). Recommendations are organized according to both ethical principles and stakeholder group; these are mutually inclusive and the user may choose to apply either the broad or specific recommendations based on their needs. While our collective experience is drawn from an Ontario perspective, our analysis and recommendations may be informative to other provinces and territories across Canada.

## METHODS

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This paper was developed by a multidisciplinary group of authors using an iterative and consensus-based process. The authors first came together as members of a small working group of the Joint Centre for Bioethics (JCB) Task Force on Physician Assisted Death, which has released its own report.<sup>7</sup> The smaller working group had diverse representation from bioethics, medicine, occupational therapy, law, policy, health administration and patient advocacy. Members were actively involved in healthcare delivery in community, acute care and mental health sectors. Those who authored this document all have extensive bioethics training and are current [practicing healthcare ethicists](#).

The authors reviewed existing literature, policies, discussions from the JCB Task Force deliberations and international experience with PAD. Discussion of previous end-of-life (EOL) experiences and PAD stories in the public realm helped shape the development of archetypal cases. From discussion of the pressing ethical issues in these cases, an iterative, inductive process was followed to first develop and then revise a list of the most relevant ethical principles. Through exploration of these cases, a conceptual representation of the ideal patient and HCP experience from the initial request to eventual act of PAD was developed. Through this comparative process, the gaps, needs and potential mitigation strategies and recommendations were identified. These cases further highlighted the multiple and various interprofessional roles involved in the patient journey towards PAD. The cases have been fashioned into composite case studies to capture a range of essential ethical and practical dimensions of PAD operationalization. Brief versions are included in Table 2 with more fulsome ethical analysis to be published separately. In discussion of hypothetical PAD cases, several key issues left unresolved by the Carter decision were identified. They are included herein and the authors recommend that further discussion is needed on each of these ethically relevant topics. The need for additional expertise was identified and an external consultation process was undertaken to capture perspectives potentially unrepresented within the working group. Input was sought from key stakeholder groups who will set PAD policy and practice standards, and those who will deliver and receive [PAD related care](#). During this time, the Canadian Federal<sup>8</sup> and Provincial-Territorial<sup>9</sup> reports became available. The authors reviewed these new reports and feedback and consensus was achieved on all revisions and final content.

A limitation is that the inductive approach for generating the ethical principles may not capture the full gamut of possible issues. However, this approach has been adopted in similarly complex situations such as pandemic planning and drug shortages. Additionally, the descriptive conceptualization of the ideal patient and HCP experience was based on evidence from other jurisdictions with PAD, working group member skill, training and experience, which collectively may not be exhaustive. As well, input from some stakeholder groups was less comprehensive than others. Ultimately, this document is meant to stimulate discussion, rather than present definitive conclusions.

## WORKING ASSUMPTIONS

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- While debate may persist on the practice of PAD, eligible residents of Canada will nonetheless be able to legally request and receive PAD.
- Per the Supreme Court of Canada (SCC) *Carter* ruling, PAD encompasses both situations where a physician either provides or administers medication that intentionally brings about the patient's death, at the request of the patient (para 40).<sup>1</sup> Additionally, the request must be made by a capable individual

who has a grievous and irremediable condition. There is no requirement for the condition to be terminal, physical in nature or for the individual to be in the final stage of life (para 66).<sup>1</sup>

- The term physician-assisted suicide has been used to describe situations where the lethal medications are self-administered by the patient. However ongoing use of the word ‘suicide’ in reference to PAD should be avoided to prevent conflation with the more commonly understood use of the word in those tragic situations where “someone plans out or acts upon self-destructive thoughts and feelings, often while they are experiencing overwhelming stress.”<sup>10</sup> Many suicidal patients experience hopelessness and a desire to die; in most situations these feelings can be ameliorated and suicide can be prevented. While some patients requesting PAD may be partly motivated by lack of hope about a meaningful future, most continue to express a desire to live and actively participate in their life until the time of their planned death. Others may be justifiably expressing little hope for their future. This does not implicitly make them incapable or ineligible to request PAD. Distinguishing between capable and potentially incapable requests for PAD will especially be critical where mental health factors play a large role in the person’s suffering.
- The number of patients that will make inquiries about PAD will exceed those that make a formal request for PAD. A formal request for PAD will initiate a process of assessment for eligibility criteria, an exploration of the patient’s goals of care, fears, options for symptom management and [EOL care](#) options, etc. Contemplation of PAD either through an inquiry or formal request for PAD is an individualized process that may be supported by any number of HCPs, spiritual leaders, practicing healthcare ethicists or organizations.
- When a patient makes a request for PAD, hastened death is only one possible outcome of that request. From other jurisdictions, approved PAD requests range from 57-78%<sup>11</sup> and completion rates range from around 65% in Oregon.<sup>12,13</sup> Enhancing palliative care access, supports and services as outlined in *The way forward national framework*<sup>14</sup> will help address the concerns of the majority of patients, including those seeking PAD.
- Although the emphasis in the terminology of PAD is on the role of the physician, given the interprofessional reality of current healthcare practice, the participation of other health professionals and service providers is required. The interprofessional nature of PAD related care is also highlighted in the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying.<sup>9</sup>
- Society has collectively, though not unanimously asked for PAD as an EOL care option in Canada. With implementation of the *Carter* decision, some HCPs will be asked to provide PAD for eligible patients who request it. However, HCPs are not currently socialized to consider either PAD or the act of intentionally hastening death as an option for EOL care. When HCPs accept these duties, it should be anticipated that some will experience complex moral and emotional responses given the gravity of suffering involved, the inability to remedy it and the unsettling but defensible terrain of practice that causes death. Since these HCPs are fulfilling a duty to society, there is a reciprocal role for society and the provider community to support them. Accordingly, employers, professional associations and others must anticipate this response and appropriately plan, resource and institute proactive support systems.<sup>15,16</sup>
- Based on experiences from other jurisdictions, PAD will occur in multiple settings including hospitals, hospices, long-term care facilities and in the patient’s home.<sup>17</sup>

## KEY ETHICAL ISSUES

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Implementing PAD poses important legal and ethical questions and requires healthcare organizations and providers to examine their corresponding duties and obligations related to PAD. In doing so, there are numerous ethical tensions that must be considered, three of which will be discussed here. Additional legal and ethical issues of PAD were left unresolved by the *Carter* decision and will be discussed later in this paper.

## ETHICAL TENSIONS

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### **1) *Reconciling the ethical obligation for physicians and other healthcare providers to “do no harm” with the obligation to respect patient autonomy and potentially hasten death if PAD eligibility criteria are met.***

Physicians and all HCPs have an ethical obligation not to harm patients who have entrusted their care to them. This concept of non-maleficence is a fundamental and shared ethical principle in healthcare and is central to the fiduciary relationship, codes of ethics and the Hippocratic Oath. PAD challenges the nature of this fiduciary relationship by making a request of a HCP to intentionally cause the death of a patient. Furthermore, PAD challenges the assumption that death is necessarily considered harmful in all situations, especially in the face of a grievous and irremediable medical condition. While in some situations harm may be considered objectively, perceptions and experiences of suffering are inherently subjective and the lived experiences of the patient must be acknowledged. Decisions to withdraw or withhold life sustaining treatments, palliative sedation and PAD reflect instances where death may not be the more harmful option for the patient; instead ongoing life in the grievous and irremediable state may be seen as the more harmful option by the patient. In these cases the request for PAD may be the result of capable, well-reasoned deliberation. Respecting autonomy means honouring the capable wishes of an individual patient. Respect for a patient’s autonomy requires deliberate consideration of their capacity, including the concept that a wish to die is not necessarily the result of incapacity.

### **2) *Balancing access to PAD with conscientious objection (CO).***

In the healthcare context, CO involves the rejection of some action by a HCP, primarily because the action would violate a personal, deeply held moral or ethical value.<sup>18</sup> A HCP’s involvement in PAD may range from counseling around all available EOL care treatment options to the actual provision of PAD. HCP providers may be willing to participate in some aspects of PAD related care (e.g. discuss EOL care option, provide ongoing pain and symptom management), but conscientiously object to others (e.g. prescribe or administer PAD medications). Both legal and ethical dimensions of this tension must be considered.

Reasons for permitting CO can be derived from clinician rights under the *Charter of Rights and Freedoms*<sup>19</sup> and the following ethically relevant considerations identified by the American Thoracic Society (ATS) policy statement for CO in the intensive care unit: 1) protect the clinicians’ moral integrity 2) respect clinicians’ autonomy 3) improve the quality of medical care by promoting a medical environment that respects diversity of opinion and culture 4) identify needed changes in professional norms and practices as conscientious objectors may highlight areas for review or revision.<sup>20</sup>

Conversely, to impede access to PAD for eligible patients invokes individual rights to life, liberty and security of the person protected by the *Charter*. Thus patient access to PAD must not be impeded or

frustrated as a result of COs. Other considerations are the role of physicians in the public healthcare system, the duties they owe patients as a fiduciary, and the inherent power differential that exists between physicians and their patients. Four ethical reasons not to accommodate CO are suggested in the ATS policy statement that are relevant in the context of PAD: 1) honour core professional commitments to promote patient's best interests (as determined by the patient) and not abandon patients 2) protect vulnerable patients who lack the choice of clinician, advance notice of the clinician's CO, or are severely constrained in seeking out a new clinician or institution 3) prevent excessive hardship on other clinicians or institutions and 4) avoid invidious discrimination.<sup>20</sup>

Institutions (via their mission, vision or values statements, etc.) may espouse core values and principles of practice but an institution itself does not reach the threshold of conscience.<sup>7</sup> In some regions, faith-based intuitions are permitted to not provide services that are contrary to their religious beliefs.<sup>21</sup> Depending on geographic location, nature of illness or other factors, patients may not have a choice of the institution in which they receive care. For patients receiving active care and wishing to explore PAD as an EOL option within religious institutions, the complete denial of PAD related care (including counseling and support around all EOL care options and making effective referral and enabling transfer) places inequitable barriers to access and potentially increases suffering for these patients. Some patients requesting PAD may already be experiencing vulnerabilities due to their illness, mobility issues or dependence on care from others and initial inability to access PAD related support may increase this vulnerability. Permitting institutional CO has the potential to disproportionately place hardships on the patient rather than the institution. The potential for institutional CO in rural or remote areas further compounds the existing inequities in access to care. Any allowances for institutional opt-out from PAD should be accompanied by a requirement for clear and transparent notification to the public that such services are not available, though referral and transfer will be provided if needed. Furthermore, patient who find themselves within care of religious institutions must not bear additional burdens or prolongation of their suffering as a result of a request for PAD that is contrary to the religious beliefs of that institution.

As uncertainty persists around PAD legislation and policy, the full impact of CO on PAD implementation is unknown. However, recent data from primary care providers across Canada demonstrates that 12% are willing to be involved based on the belief that PAD is a patient's decision alone, and 53% would be willing if appropriate checks and balances were in place.<sup>6</sup> Facilitating the connections between these willing providers and patients inquiring or requesting PAD will be essential. Furthermore, PAD is neither unforeseeable nor typically an emergency; HCPs and institutions will have time to anticipate, plan and be prepared for the potential need to transfer care of patients requesting PAD

Nonetheless, it is important that the issue is approached not as a problem of intractable competing rights, but rather as a reasonable balancing of the rights and interests of both the patient and HCP. There is no question that access to PAD cannot be frustrated, but in maintaining access the conscience and beliefs of HCPs must still be considered. Both providers of and objectors to PAD will to experience some degree of moral ambiguity or distress. Care must be taken to provide support for all. Ultimately, objections based on faith, values or logistics must not hinder the access of eligible patients seeking PAD.

### **3) Mitigating potential risk of harm to vulnerable populations without creating unreasonable access barriers.**

Requests for PAD may be triggered by current suffering, anticipation or fear of future suffering, a desire for self-determined time of death, a desire not to burden *family* or any combination thereof. In Oregon, the most common end of life concerns of those who requested a prescription for PAD were loss of autonomy, decreasing ability to participate in activities that made life enjoyable and loss of dignity.<sup>12</sup> When a request for PAD is made, it is essential that an informed, collaborative decision-making process occurs. This process must be well supported by competent HCPs who are proficient with values-based goals of care conversations and capacity assessments. Parameters must be put into place to ensure that rigorous safeguards exist such that no one unnecessarily ends their life due to a lack of information or access to all care options (including support for ongoing life or other EOL options) that could meet their needs. Further, safeguards must be in place so that vulnerable individuals or groups are not pressured to pursue or forego PAD, for example, due to biased quality of life assessments by others. Individuals who are living with or dying from illness, disease or disability may experience vulnerability through their dependency on others and the health system to meet their needs, alleviate suffering and assist with activities of daily living. The role of the HCP in these conversations is to help the patient articulate goals of care, address fears, and understand the factors motivating the request for PAD in order to identify potential vulnerabilities or concerns that might be remediable (such as lack of resources for care, or anxieties about burdening others).

However, mitigating these risks must be balanced with ensuring that those who meet SCC *Carter* eligibility criteria do not face barriers in accessing PAD. The *Carter* decision did not limit PAD to patients with terminal illnesses; rather, it refers to grievous and irremediable conditions. Operationalization of the *Carter* criteria must not exclude patients on the sole basis of their illness (e.g. mental health and chronic pain). It could be argued that failure to extend PAD to non-terminal patients who meet the *Carter* criteria would infringe Sec. 7 *Charter* rights to life, liberty and security of the person such that the deprivation is inconsistent with principles of fundamental justice and that this infringement would not be justified under Sec 1.

## ETHICAL PRINCIPLES

Based on our collective experience as clinicians, practicing healthcare ethicists, lawyers, policy-makers, patients, and family members, we propose six overarching substantive and procedural ethical principles that guide our recommendations contained herein. See Table 1 for an overview of the six principles and their associated goals. The principles are listed alphabetically and are not rank-ordered. Working definitions for these principles can be found in Appendix I or by following the hyperlink.

**Table 1: PAD Overarching Ethical Principles & Associated Goals**

Principle	Associated Goal (s)
<b><u>Accountability</u></b>	<ul style="list-style-type: none"> <li>Implement PAD in a manner that clearly identifies lines of authority, an oversight mechanism and associated responsibilities for all relevant stakeholders, including boards of directors, patients, their families, HCPs, professional colleges and associations, and policy makers such that public trust in the process is preserved and enhanced.</li> </ul>
<b><u>Collaboration</u></b>	<ul style="list-style-type: none"> <li>Build, preserve and strengthen inter-professional, inter-institutional, <i>inter-sectoral</i>, and where appropriate, inter-provincial/territorial collaborations and partnerships to facilitate consistent implementation of PAD.</li> <li>Partner to collectively establish evidence-based best practices.</li> </ul>
<b><u>Dignity</u></b>	<ul style="list-style-type: none"> <li>Recognize and preserve the inherent worth of each person and their individual experience of pain and suffering and associated decisions across the life continuum.</li> </ul>
<b><u>Equity</u></b>	<ul style="list-style-type: none"> <li>Promote fair and just access to PAD for all eligible individuals irrespective of healthcare setting or geographic area.</li> <li>Support procedural fairness such that like PAD cases are treated in a similar manner and dissimilar PAD cases are treated in a manner that takes into account the differences.</li> </ul>
<b><u>Respect</u></b>	<ul style="list-style-type: none"> <li>Demonstrate the highest regard for persons, organizations and their associated beliefs and values related to PAD and the myriad of concepts, issues and practices associated with it.</li> </ul>
<b><u>Transparency</u></b>	<ul style="list-style-type: none"> <li>Foster and maintain public, patient, and healthcare provider trust and confidence in health system.</li> </ul>

## ILLUSTRATIVE CASES

The following cases informed discussion and development of recommendations. They attempt to highlight potential operational and challenges in the application of the *Carter* decision. Further discussion of these cases with an ethical analysis is in progress and will be published separately.

**Table 2: Illustrative Cases**

### **Case 1: Request for PAD at the time of diagnosis**

Nathan supported his father through his slow death over a number of years with Huntington's disease. He has recently discovered that he carries the Huntington gene and has come to the conclusion that he cannot face the same experience. He approaches his genetic counselor to discuss a planned death in the near future.

### **Case 2: The role of a proportionate waiting period**

Anita is a fifty-three-year old woman, diagnosed with colon cancer with widespread metastases two months ago. Chemotherapy was stopped due to repeated infections and intolerable side effects. Her disease is rapidly progressing and she has developed severe swelling in her legs, which is now preventing her from being able to walk. She admitted herself to hospice care with uncontrolled nausea, vomiting, diarrhea, and pain. While medication can alleviate some of her symptoms she is still uncomfortable most of the day. She made her first request for PAD three days ago and has had some discussion about the process. She now tells her nurses that she cannot tolerate living like this any longer. Given the rapid progression of her disease, she is not expected to live more than a few weeks.

### **Case 3: Conscientious objection by a sole practitioner in a rural community**

Ghita is an eighty-seven year old woman with severe spinal stenosis. She has recently become wheelchair bound and is losing the ability to use her hands. She continues to be in severe pain despite multiple medications. She is no longer able to participate in activities she finds meaningful and she is ready to plan her death. She asks her family physician about PAD. Her family MD is the only practitioner in town and he is uncomfortable talking about PAD. He suggests that she will need to find someone else to discuss this with.

### **Case 4: Subjective assessments of quality of life, concurrent mental health considerations and capacity assessments**

Thom is 48 and has been living with quadriplegia and an acquired brain injury since a motor vehicle accident 18 months ago. He can speak and direct his own care, but is dependent upon family for managing his finances. He had been adjusting well to his new life and was starting to participate in more activities outside the house. However, he has recently been withdrawing and experiencing emotional outbursts and has stated that feels his life has little meaning or purpose.

Thom raises the idea of PAD with his family physician who readily agrees that such a life would not be worth living. They start to plan for PAD. His wish for PAD, if fulfilled, would likely shorten Thom's life significantly.

### **Case 5: Who defines hope? How probable does possible improvement need to be to negate PAD?**

Morris has been living with progressive MS for 30 years and now uses an electric wheelchair. Being well informed on what his future holds, he has repeatedly stated that he does not want to carry on into the last stages of the disease that will deprive him of his independence, cognitive and functional abilities. He feels this would mean living a life which offers him little sense of meaning or purpose, and which amount to simply 'waiting for God'. He has tried multiple experimental treatments at his clinician's recommendation with no improvement. He now approaches his neurologist about PAD. All his clinicians and his family are worried he is giving up too soon, especially in light of new clinical trials.

**Case 6: A PAD request in the setting of a medical condition with possible concurrent depression.**

Esther has had a very successful and rewarding life and career. In her late 50's she developed a brain tumour that is inoperable and incurable. As her functional abilities diminished, she was increasingly unable to engage in work and decided to retire six months ago. She has become increasingly withdrawn and her mood is very low. She feels there is little left to live for now. She is very fixated on the prospect that she will soon have to rely on others for personal care. She is requesting an arranged death to avoid more of the daily distress that she anticipates will be her reality until the tumour eventually causes her death.

**Case 7: A request for PAD in the context of mental illness**

Daryl has lived with refractory depression for most of his adult life. At 55, Daryl is considering PAD as the only way he can relieve the intractable pain and distress in his life that has not been improved adequately by all other attempts to manage it. He has asked for information on the possibility of PAD from his mental health team.

## UNRESOLVED ISSUES ARISING FROM THE *CARTER* DECISION

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The decision in *Carter* was made based on individual cases and could not cover all eventualities of PAD operationalization. In discussion of hypothetical cases and experiences from other jurisdictions, three unresolved issues emerge that merit further discussion.

### THE DEFINITION OF ADULT

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The SCC decision indicates that PAD will be permissible in capable adults only. However the term adult is not well defined with variable age limits contained in different statutes. Some international jurisdictions have allowed PAD for children as young as 12, with parental involvement.<sup>17</sup> In Canada, the age of majority, set by each province or territory, has been suggested as a possible threshold.<sup>8</sup> PAD entails consenting to a treatment (or treatment plan) and variation exists among the provinces with regards to age of consent for treatment decisions. In Ontario, for example, there is no legally defined age of consent for treatment decisions; rather capacity determines if a patient can make a treatment decision. However, even in Ontario, age requirements have been legislated for specific healthcare decisions. Both organ donation and substitute decision-making require an individual to be 16 years or older (with the exception of substitute decision-making for one's child). This means that at age 16, a person may decide to withhold or withdraw life-sustaining interventions for someone else but may not elect for PAD, if eligible. PAD overlaps multiple legal jurisdictions and complicates the age dilemma: PAD crosses healthcare and criminal law, and consequently provincial and federal regulation. Unless there is national agreement on the definition of adult, or deciding to accept consent for PAD based on capacity (as recommended by the Provincial-Territorial Expert Advisory Group)<sup>9</sup>, equitable access across the country is undermined.

### THE ROLE OF ADVANCE DIRECTIVES, LIVING WILLS AND PRIOR CAPABLE WISHES

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The SCC decision stipulates that requests for PAD must come from a capable patient. Advance care planning, living wills, instructions within a power of attorney and advance directives are all a way for capable individuals to express wishes for future care (recognized legally in Ontario as prior capable wishes). While the legality of these documents to constitute consent varies by province (e.g. in Ontario a capable individual must always be asked to provide consent for treatment), their purpose is to allow a capable person to express wishes about their care in the event of a loss of decision-making capacity. These will hereafter be referred to collectively as 'advance wishes.'

It is conceivable that patients may express a capable wish for future PAD if they develop conditions that they worry will lead to intolerable suffering concurrent loss of capacity (e.g. dementia). Based on the SCC decision, the issues of advance wishes for PAD remains uncertain; however decisions to withhold or withdraw life-sustaining treatments for patients will continue to be available under existing legislation.

One challenge with advance wishes and PAD stems from the temporal relationship of the grievous state and assistance with death. Both 'grievous' and 'intolerable suffering' remain subjective person-defined experiences; however, the perceived permanence of these states is debatable. It is impossible to know in advance if that which a person imagines to be grievous suffering is sufficiently predictive of the actual experience of their future incapable self. Advance wishes for PAD would appear to stem from anticipation

of things such as future experiences of suffering, eventual loss of dignity and the erosion of ‘one’s self.’ None of these are present contemporaneously with the advance wish for PAD – they are anticipated.

Considering PAD by advance wishes raises complex issues around personhood, narrative identity, psychological continuity and critical versus experiential interests.<sup>a</sup> Assuming the advance wish meets the legal requirements at the time of original request, the question of how it could be applied in future states of incapacity and uncertain voluntariness is complicated. Clear questions arise:

- Are we sufficiently able to contemplate how our future selves will experience (predicted) suffering?
- Based on individual’s ability to adapt to morbidity over time, is it acceptable to consider that one’s current perceptions of dignity and suffering will remain constant throughout one’s life?
- How can quality of life judgment biases be mitigated if PAD by proxy consent is permitted? Will there be a bias toward permitting PAD for patients with ‘challenging’ behaviours versus the placidly confused?
- Is there a need for expert consultation when drafting advance wishes for PAD so that specific criteria are included to mitigate potential harm to incapable patients or invalidate the advance wishes?
- What are the additional requirements to make advance wishes for PAD ethically permissible?
- Who will determine that the conditions of the advance wish for PAD have been met?
- What are the additional considerations for substitute decision-making and informed consent for PAD?

Despite the many outstanding issues, the perceived indignity anticipated by those facing future incapacity (because of dementia or other conditions) cannot be ignored. In light of the uncertainties, as Canada gains experience with PAD, these concerns merit further exploration, including considering the possibility of clearly articulated parameters to permit advance wishes for PAD.

At this point our collective understanding of advance care planning and advance directives is not sufficiently nuanced to ensure that advance wishes convey an adequate exploration of all possible experiences of future incapacity. It would seem prudent to convene a specific working group to examine this complexity and develop a reasoned framework for considering when, if ever, it could be included in PAD provision in Canada. Guidance should be sought from jurisdictions that have already implemented PAD for patients with dementia, and other diseases that result in similar states of incapacity.<sup>17</sup>

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<sup>a</sup> Most of these ideas have been described and debated for some time. The concept of personhood explores what it is to be a ‘person’, rather than simply a human. Tom Kitwood has written extensively about this in the context of dementia specifically, where cognitive decline appears to erode the identity of the person affected. (See Dewing J. (2008), Personhood and dementia: revisiting Tom Kitwood’s ideas. *International Journal of Older People Nursing*, 3: 3–13. doi: 10.1111/j.1748-3743.2007.00103.x ).

Narrative identity considers the idea that one’s story over time is the source of individual identity. The notion of psychological continuity suggests that personhood is dependent upon sustaining a single identity over time. Critical interests were described by Ronald Dworkin as an individual’s beliefs about what is important to a good life overall – beliefs, values and desires. These can be reflected after death (or incapacity) by a last will and testament (or advance directive). Experiential interests are related to an individual’s ongoing experience of living – having desires and needs fulfilled. An excellent exploration of these latter concepts can be found in Menzel PT & Steinbock B. (2013). Advance directives, dementia, and physician-assisted death. *Journal of Law, Medicine and Ethics*, 41(2):484-500.

## RESIDENCY AND PAD “TOURISM”

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The SCC ruling does not specify a residency requirement that eligible individuals must be legal residents of Canada or establish residency in the province in which they are seeking to access PAD. However, Quebec’s Bill 52: An Act Respecting End-of-Life Care<sup>22</sup> does include a residency requirement, which mandates that individuals be insured under Quebec’s health insurance program. Provinces will have to determine if PAD will be an insured service eligible to out-of-province patients under the portability requirement of the *Canada Health Act*<sup>23</sup>. Additionally, a decision will have to be made if non-residents of Canada (commonly referred to as medical tourists) will be permitted to travel to Canada with the intent to obtain PAD. Switzerland is currently the only jurisdiction that will help non-residents to die.

## RECOMMENDATIONS

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The recommendations outlined below are organized first by the identified [ethical principles](#) and then by [stakeholder group](#). The ethical principle recommendations are meant to apply broadly; some recommendations align with several ethical principles and may be duplicated under multiple principles where deemed integral. Some individuals, groups or organizations may choose to draw recommendations from multiple stakeholder groups depending on their specific roles (e.g. organizations with both regulatory and educational mandates).

### RECOMMENDATIONS BY ETHICAL PRINCIPLE

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#### **Accountability:**

*Implement PAD in a manner that clearly identifies an oversight mechanism and associated responsibilities for all relevant stakeholders, including, patients, their families, HCPs, professional colleges and associations, and policy makers by:*

- 1) Explicitly identifying lines of decisional authority at all levels of the institution and region;
- 2) Adhering consistently to the PAD eligibility criteria, applications of safeguards and associated processes (including appeal procedures) and oversight mechanisms for PAD;
- 3) Clarifying any relevant procedural differences between patient self-administered PAD medications versus physician administration of PAD medications;
- 4) Ensuring rigorous but not unduly burdensome oversight of PAD;
- 5) Developing and following standards of care and evidence-based best practices whenever possible;
- 6) Educating members of the public to provide reassurance that some individuals or groups will not be pressured into PAD or subjected to it without their consent;
- 7) Facilitating HCPs to receive appropriate education to maintain scope of practice and competency on PAD (e.g. counseling, referral, prescribing, dispensing, administering);
- 8) Ensuring HCPs and institutions respect the beliefs of conscientious objectors while accepting the responsibilities for transfer and non-abandonment of patients who are requesting PAD;
- 9) Developing an accessible network or system that facilitates but does not hinder the transfer of care in cases of conscientious objection. The burden of identifying willing providers should neither be borne by the patient nor result in adverse clinical outcomes; and
- 10) Developing a system for reporting cases of PAD, including a strategy for review, evaluation and revision of processes, procedures and safeguards.

#### **Collaboration:**

*Build, preserve and strengthen inter-professional, inter-institutional, [inter-sectoral](#), and where appropriate, inter-provincial/territorial collaborations and partnerships by:*

- 1) Embracing a shared commitment to comprehensive end-of-life care for patients regardless of care setting, geographic location or eligibility for PAD;

- 2) Recognizing that provision of the full spectrum of services and supports involved in PAD requires interprofessional collaboration and an appreciation of unique roles and associated responsibilities in providing PAD and related support;
- 3) Establishing, encouraging, and enabling open communication and coordination amongst health professionals, health institutions, and health sectors;
- 4) Engaging with relevant stakeholder groups to ensure their perspectives are considered and respected in resulting legislation, policies and procedures;
- 5) Developing a network or system that facilitates the timely communication and/or transfer of care between conscientious objectors and willing providers of PAD (this network could be at local, regional or provincial levels);
- 6) Encouraging sharing of information and resources across health sectors, health institutions, and, where appropriate, provinces/territories;
- 7) Contributing collectively to knowledge acquisition and translation on PAD practices, effects on patients and providers and system supports for PAD; and
- 8) Applying consistently a shared ethical framework and applicable policies.

### **Dignity:**

*Recognize the inherent worth of each person and their individual values, beliefs and experience of pain and suffering by:*

- 1) Demonstrating compassion and minimizing pain and suffering of patients in all elements of EOL care and transfer of care through the application of relevant evidence-based best practices;
- 2) Ensuring adequate competency of all providers to deliver care in order to achieve the desired outcome for all options of EOL care;
- 3) Facilitating timely conversations about and access to PAD for eligible patients who have requested it;
- 4) Enabling patients to receive PAD in the most appropriate setting based on the patient's wishes and available resources;
- 5) Providing appropriate care and support for patients deemed ineligible for PAD;
- 6) Creating an environment that respects individual values and autonomy;
- 7) Educating HCP providers to perform skilled capacity assessments to obtain informed consent from eligible requesters of PAD;
- 8) Recognizing and respecting that some individuals may wish to conscientiously object to PAD;
- 9) Providing HCPs who provide PAD with ongoing associated support, e.g. education, professional advice, and assistance coping with associated distress; and
- 10) Developing a proactive support system for providers experiencing moral, emotional and psychological distress as a result of anticipation of, conscientious objection to or involvement with PAD.

## **Equity:**

*Promote just/fair access to PAD for eligible patients by:*

- 1) Ensuring access to information and practices supporting PAD are not subject to barriers or impediments without clear, legally and ethically defensible rationales. As with other current healthcare provision, geographic or procedural variables may affect access; mitigation strategies must be developed so that these are not borne disproportionately by any patient or group. Additional resources may be required to prevent adverse clinical outcomes that could potentially arise from these barriers or impediments;
- 2) Encourage fair allocation of responsibility for providing PAD such that the system does not unduly burden any particular provider, group of providers, health sector, or institution;
- 3) Not discriminating against patients based on factors extraneous to their eligibility for PAD (e.g., social status, disease, etc.);
- 4) Consistently applying a shared ethical framework and applicable policies; and
- 5) Considering procedural fairness in the development of PAD processes for both similar and dissimilar cases (e.g. differential waiting periods, terminal vs. non-terminal cases, mental health considerations).

## **Respect:**

*Demonstrate the highest regard for persons and institutions and their associated beliefs and values related to PAD by:*

- 1) Ensuring education for HCPs on facilitating discussion on the full range of EOL care options including palliative care, continuous palliative sedation therapy, other non-PAD options, and PAD;
- 2) Adopting an approach to EOL care whereby death and dying are normalized as part of the full continuum of a patient's life;
- 3) Educating the public around EOL care options, including normalizing the dying process as part of the continuum of life and death;
- 4) Integrating early advance care planning discussions to prepare patients and HCPs for in-the-moment decision making at the end-of-life;
- 5) Ensuring HCPs engage in values discussions with patients surrounding all elements of their care;
- 6) Ensuring HCPs perform capacity assessments in accordance with relevant legislation;
- 7) Ensuring HCPs facilitate collaborative and comprehensive informed consent discussions regarding PAD with patients requesting physician assisted dying regarding the risks, benefits, and alternatives to PAD;
- 8) Adhering to relevant standards of care and evidence-based best practices;
- 9) Informing and educating health providers about risks, benefits and appropriate use of PAD, including risk mitigation strategies;
- 10) Accommodating reasonable, conscientious objection to participating in PAD for HCPs;
- 11) Requiring that conscientious objectors of PAD must arrange the timely transfer of care to a HCP, agency or institution willing to provide PAD related care; and

- 12) Developing a proactive support system for providers experiencing moral, emotional and psychological distress as a result of anticipation of, conscientious objection to or involvement with PAD.

### **Transparency:**

*Foster and maintain public, patient, and healthcare provider trust and confidence in health system by:*

- 1) Communicating clearly the PAD eligibility criteria, associated processes (including an appeal mechanism) and oversight for PAD;
- 2) Making decisions in an open, consistent and ethically informed way with clearly defined decision-making authority and accountability at relevant governance levels including institutional, provincial/territorial and federal;
- 3) Communicating clearly the requirements for patient transfer in cases of conscientious objection so that HCPs and patients are aware of their corresponding rights and obligations;
- 4) Enabling a system for transfer of care, whereby conscientious objectors and providers of PAD can communicate without risk of discrimination based on their beliefs or actions;
- 5) Making a commitment to continuously capture and integrate lessons learned in order to enhance the PAD process; and
- 6) Publicly sharing data regarding utilization, patient demographics, case reviews and potentially inappropriate application of PAD.

## **RECOMMENDATIONS BY STAKEHOLDER GROUP**

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### **Legislators (Provincial, Territorial and Federal):**

- 1) Develop legislation to outline all the elements of implementing PAD (e.g. specifying relevant definitions, eligibility criteria, process, conscientious objection and data recording);
- 2) Develop legislation that explicitly describes which HCPs can be involved with PAD and in what capacity (counseling, prescribing, dispensing, administering etc.) and indemnify those who are appropriately involved; and
- 3) Work in collaboration with regulatory bodies and professional associations to develop evidence based integrated protocols for the practice of assisted dying.

### **Ministries of Health:**

- 1) Ensure fair access to both PAD and counseling around the full range of EOL options including PAD, by working towards coordinated strategies to improve EOL care including palliative care. This plan should apply across the provinces, territories, regions, health organizations, among health sectors (e.g., acute and community based services), and among healthcare professionals;
- 2) Provide financial and logistical support for a referral and transfer system to facilitate access to PAD, including in situations of conscientious objection (e.g. develop a comprehensive list of willing providers);
- 3) Encourage collaboration among local health networks, healthcare organizations and interprofessional colleges and associations to establish common policies and procedures;
- 4) Work with appropriate regulatory/oversight bodies to develop system of reporting, tracking and monitoring (e.g. death certificate, billing codes);

- 5) Meet with counterparts in other provinces to reduce inconsistencies and irregularities between provinces to work towards a national strategy;
- 6) Maintain a reporting system that monitors all requests for PAD, the irremediable condition, potential vulnerable conditions and rates of PAD completion; and
- 7) Develop a system for revisions and review that make use of existing bodies/agencies and relevant expertise.

### **Organizations with Regulatory roles:**

- 1) Assess and ensure that HCPs have received capacity-building and competency-based training on counseling around EOL care (including goals of care), advance care planning and PAD. Providers must also have attained competency with informed consent and capacity assessments relevant to the EOL context;
- 2) Develop policies on EOL care that include full range of EOL options and address professional obligations for counseling and providing PAD related care in all healthcare settings (including home based care). These policies should be grounded in the ethical principles of accountability, collaboration, dignity, equity, respect and transparency;
- 3) For professions involved with discussing, prescribing, dispensing or administering PAD, colleges and associations to provide competency-based training specific to the skills required;
- 4) Develop policies around conscientious objection that consider the following:
  - a. Define the positive obligations of professionals who choose to conscientiously object to participation with PAD;
  - b. Ensure the accommodation of CO will not impede a patient's timely access to information, counseling or provision of PAD;
  - c. Ensure the accommodation will not create excessive hardships for other clinicians or institutions; and
  - d. Ensure the CO is based on religious, faith or values-based beliefs and not on invidious discrimination.
- 5) Collaborate with the development of a registry of providers willing to discuss or assist with PAD to facilitate the referral and transfer of patients. Access and dissemination of this registry must balance safeguarding the practitioners from possible vexatious/malicious intent with preventing access barriers for patients requesting PAD;
- 6) Ensure HCPs understand the interprofessional elements of PAD and both shared and unique roles in PAD;
- 7) Be mindful of the fact that PAD is an interdisciplinary endeavor when framing policies and guidelines;
- 8) Develop a system for revisions and review of policies and practices that make use of existing bodies/agencies and relevant expertise;
- 9) Engage the public and encourage public dialogue around end-of-life care including advance care planning, palliative care and physician-assisted death; and
- 10) Contemplate and prepare for the sensitive nature of complaints, inquiries and discipline process for PAD related issues.

### **Professional Associations/Colleges/Societies:**

- 1) Develop collaboratively with other groups comprehensive EOL care strategies that places PAD within a continuum of EOL care options;
- 2) Develop policies and guidelines that frame PAD as an interdisciplinary endeavor. These documents outlining EOL care should include discussion of the full range of possible options for care. They must address interprofessional roles for counseling and providing PAD related care in all healthcare settings (including home based care). These policies should be grounded in the ethical principles of respect, collaboration, dignity, equity, accountability and transparency;
- 3) Collaborate with the development of a registry of providers willing to discuss or assist with PAD to facilitate the referral and transfer of patients. Access and dissemination of this registry must balance safeguarding the practitioners from possible vexatious/malicious intent with preventing access barriers for patients requesting PAD;
- 4) Develop policies around conscientious objection that consider the following:
  - a. Define the positive obligations of professionals who choose to conscientiously object to participation in PAD;
  - b. Ensure the accommodation of CO will not impede a patient's timely access to information, counseling or provision of PAD;
  - c. Ensure the accommodation will not create excessive hardships for other clinicians or institutions; and
  - d. Ensure the CO is based on religious, faith or values-based beliefs and not on invidious discrimination.
- 5) Facilitate interprofessional education and communication among HCP to understand both shared and unique roles in PAD;
- 6) Provide capacity-building and competency-based training on counseling around EOL care (including goals of care), advance care planning and PAD. Training should also include informed consent and capacity assessments as relevant to the EOL context;
- 7) Provide competency-based training or guidance on specific skill development for professions involved with discussing, prescribing, dispensing or administering PAD;
- 8) Provide confidential support for both PAD providers and conscientious objectors;
- 9) Develop a proactive support system for providers experiencing moral distress as a result of anticipation or involvement with PAD; and
- 10) Encourage and support public dialogue around end-of-life care including advance care planning, palliative care and PAD.

### **Organizational Providers of Healthcare Services (e.g. Hospitals, LTC facilities):**

- 1) Develop policies and procedures for PAD that at a minimum address the following:
  - a. Implement/operationalize inclusion and exclusion criteria for PAD consistent with legislation and applicable governing standards and evidence-based practice protocols.
  - b. Facilitate an appeal processes (internal and external) for contesting declined requests for PAD (including appeals of capacity assessments);
  - c. Outline a procedure for identifying physicians willing to participate in PAD to prevent overburdening of the same physicians repeatedly. Consider establishing a centralized consult service;

- d. Outline a local process for identifying conscientious objectors for all professions of HCPs to ensure procedures are in place to prevent any compromise of patient access to PAD associated care;
  - e. Develop policies around conscientious objection that consider the following:
    - i. Define the positive obligations of professionals who choose to conscientiously object to participation with PAD;
    - ii. Ensure the accommodation of CO will not impede a patient's timely access to information, counseling or provision of PAD;
    - iii. Ensure the accommodation will not create excessive hardships for other clinicians or institutions; and
    - iv. Ensure the CO is based on religious, faith or values-based beliefs and not on invidious discrimination.
  - f. Recognize and delineate the interprofessional roles and relationships between HCPs in the practice of PAD;
- 2) Inform and train all HCPs on PAD practices within the institution, including rights and obligations in cases of conscientious objection;
  - 3) Provide confidential support for both PAD providers and conscientious objectors;
  - 4) Develop a proactive support system for providers experiencing emotional, psychological or moral distress as a result of anticipation or involvement with PAD;
  - 5) Consider the role of practicing healthcare ethicists and spiritual care providers in PAD and when consultations might be particularly useful for patients and practitioners. It is also critical to consider when, why and how conscientious objection might be legitimate and defensible for these disciplines typically assisting with morally complex and values and faith-based decisions;
  - 6) Adopt an ethics framework (e.g. IDEA Ethical Decision-Making Framework<sup>24</sup>) to facilitate discussion of individual cases; and
  - 7) Foster an environment that contributes to a cultural shift, where the understanding of death and dying is viewed as an integral part of the continuum of care for patients.

### **Practicing Healthcare Providers:**

- 1) Meet professional development standards to achieve competency for the provision of PAD related care (capacity assessments, informed consent, EOL counseling, prescribing, administering, dispensing etc.);
- 2) Provide non-judgmental care to seekers of PAD;
- 3) Understand rights of conscientious objection and responsibilities for transferring care to another willing provider;
- 4) Adopt an ethics framework (e.g. IDEA Ethical Decision-Making Framework<sup>24</sup>) to facilitate discussion of individual cases; and
- 5) Involve other providers as appropriate in collaboration or consultation.

### Health Professional Training Programs:

- 1) Provide comprehensive education around EOL care that includes education on PAD.
- 2) Provide enhanced training around issues related to EOL care that includes ethics based decision-making, capacity, informed consent and addressing patient values, wishes and goals around EOL care.
- 3) Foster a learning environment that contributes to a cultural shift, where the understanding of death and dying is viewed as an integral part of the continuum of care for patients.
- 4) Consider mitigation strategies to counter the potential influence of the [\*'hidden curriculum'\*](#) on the practices associated with end-of-life.

## CONCLUSION

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While the *Carter* decision sanctioned PAD in Canada, operationalizing PAD presents challenges that sit at the multiple intersections of law, medicine, society, social relationships, ethics and the human experiences of living and dying. Even though the request originates with an individual patient, that request necessitates a systems-wide response involving multiple health professions (each with their unique role), institutions and organizations. The ethical dimensions and implications of implementing PAD are extensive and confounded by ethical tensions that must be delicately balanced. We propose a principles-based approach, embedded in our recommendations, to address the ethical dimensions and implications of implementing PAD. Principles and perspectives may conflict but approaching such tensions as competing rights should be avoided. Instead, we suggest an “overlapping consensus” approach that aims to maximally promote the shared principles, balance the interests of affected parties, reduce suffering (physical, emotional, psychological and moral) and seeks to mitigate harms where they are unavoidable.<sup>b</sup> Achieving this goal will require an iterative and nuanced approach. The *Carter* decision gives us the opportunity to redress intolerable suffering and examine EOL care in Canada, including enhancing existing palliative care. Improving the dying experience for Canadians and their support networks remains an essential endeavour.

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<sup>b</sup> Daniel Weinstock has spoken on this matter, making reference to ‘overlapping consensuses’ described by John Rawls. For more information, see: <http://www.congress2013.ca/program/events/so-are-you-still-philosopher-daniel-weinstock> Accessed 29 December 2015.

## **APPENDIX I: GLOSSARY OF TERMS**

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*To return to your previous place in the document, click on the term.*

<b><u>End-of-life (EOL) care</u></b>	is the delivery of care for patients with life limiting illnesses which may include a complement of approaches including advance care planning, goals of care discussions, treatment decisions, the provision of palliative care, symptom and pain management and PAD for eligible patients.
<b><u>Family</u></b>	is defined as two or more people, whether living together or apart, related by blood, marriage, adoption or commitment to care for one another. <sup>25</sup>
<b><u>Hidden Curriculum</u></b>	“The hidden curriculum highlights the importance and impact of structural factors on the learning process. Focusing on this level and type of influence draws our attention to, among other things, the commonly held “understandings”, customs, rituals and taken-for-granted aspects of what goes on in the life-space we call medical education. This concept also challenges medical educators to acknowledge their training institutions as both cultural entities and moral communities intimately involved in constructing definitions about what is “good” and “bad” medicine.” <sup>26</sup>
<b><u>Inter-sectoral</u></b>	the collaboration across various policy and program sectors and may operate at a policy or community level. <sup>27</sup>
<b><u>PAD Related Care</u></b>	is any care delivered by a member of the healthcare team to a patient who has requested PAD. It may involve ongoing pain and symptom management, counseling, personal care etc. while the patient considers PAD or other EOL care options.
<b><u>Patient</u></b>	a person who is a recipient of healthcare and is synonymous to client, resident or healthcare consumer depending on the setting.
<b><u>Physician Assisted Dying</u></b>	is the situation where a physician provides or administers medication that intentionally brings about the patient’s death, at the request of the patient. <sup>1</sup>
<b><u>Practicing healthcare ethicist</u></b>	is a person who “has dedicated work responsibilities within healthcare organization to provide a variety of ethics-related services which include more than one of the following: clinical and/or organizational ethics consultation; policy development and/or review; ethics education for staff; management of ethics programs (including clinical ethics committees); mentoring of staff/learners; and conducting research ethics consultations.” <sup>28</sup>
<b><u>Vulnerable</u></b>	a common and essential feature of human nature that highlights our shared experience and reciprocal responsibility to each other. <sup>29</sup> It does not only refer to a person’s characteristics but also to the situation encountered as a result of determinants such as health, access to support and potential to participate in community life. <sup>30</sup> Vulnerabilities should be seen in their broader social and political context <sup>31</sup> to highlight the potential for mitigation by addressing health, social and economic factors affecting individuals or groups.

## ETHICAL PRINCIPLE DEFINITIONS

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### Accountability

Mechanisms exist to ensure that decision makers are responsible for their actions; all have an obligation to account for, and be able to explain one's actions<sup>32</sup>

### Collaboration

Partnering with relevant stakeholders in a respectful and accountable manner such that each individual and entity understands their associated role and accountabilities.

### Dignity

The state or quality of being worthy of honour and respect of both humans and society. It belongs to every human by virtue of being human and to society as a product of the interactions between and amongst individuals, collectives and societies.<sup>33</sup>

### Equity

The quality of being equal, fair and impartial.<sup>34</sup> Equity denotes more than simply equality; it suggests that like cases be treated alike and unlike cases differently; that responses are according to the needs of the individual in relation to the needs of all.<sup>35</sup> Equity has collective social justice and public health dimensions, but also manifests in individual experience as solidarity and empathy.<sup>36</sup>

### Respect

Recognition of the individual's right to make individual choices according to their values and beliefs (within shared legal parameters). The collective endeavours of individuals may also deserve respect, though perhaps of a different degree than the level of respect afforded to individuals.

### Transparency

The quality of acting in a way that ensures that the processes by which decisions are made are open to scrutiny, and the associated rationales are publicly accessible.<sup>37</sup> Transparency is not a substitute for accountability – it is a support to it.<sup>32</sup>

## REFERENCES

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1. *Carter v Canada (Attorney General)*, 2015 SCC 5, [2015] 1.S.C.R 331. Available: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (accessed 2015 Nov 15).
2. *Criminal Code*, RSC 1985, c C-46. [July 23, 2105] (CanLII) Available: <http://canlii.ca/t/52hd3> (accessed 2016 Jan 25).
3. *Carter v Canada (Attorney General)*, 2016 SCC 4, [2016] Available: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/15696/index.do> (accessed 2016, Jan 25).
4. Angus Reid Public Opinion. Doctor-assisted suicide: Canadians and Britons would allow euthanasia under some conditions. New York. 2012 July 26: 1-8. Available: [http://angusreidglobal.com/wp-content/uploads/2012/07/2012.07.26\\_Assisted.pdf](http://angusreidglobal.com/wp-content/uploads/2012/07/2012.07.26_Assisted.pdf).
5. The forum poll. Support for assisted suicide increases across four years. Forum Research Inc. 2015 Aug 28. Available from: <http://poll.forumresearch.com/post/1365/opposition-down-sharply/> (accessed 2015 Nov 10).
6. The College of Family Physicians of Canada. CFPC ePanel 2 2015: Physician assisted suicide and euthanasia. 2015. Available: [http://www.cfpc.ca/uploadedFiles/Health\\_Policy/PDFs/ePanel\\_psa\\_results\\_EN.pdf](http://www.cfpc.ca/uploadedFiles/Health_Policy/PDFs/ePanel_psa_results_EN.pdf) (accessed 2015 July 24).
7. Joint Centre for Bioethics Taskforce on physician assisted death. After *Carter v Canada*: Physician assisted death in Canada report and recommendations. 2015 Dec 14. Available <http://jcb.utoronto.ca/docs/JCB-PAD-TaskForce-Report-2015.pdf> (accessed 2015 Dec 20).
8. External Panel on Options for a Legislative Response to *Carter v. Canada*. Consultations on physician-assisted dying: Summary of results and key findings final report 2015 Dec 15. Ottawa: Government of Canada. Available: <http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/index.html> (accessed 2016 Jan 18).
9. Provincial-Territorial expert advisory group on physician-assisted dying. Final Report. Ontario Ministry of Health and Long Term Care. 2015 Nov 30. Ontario: Queen's Printer for Ontario 2008. Available: [http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport\\_20151214\\_en.pdf](http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf) (accessed 2015 Dec 14)
10. Reiss NS, Dombeck M. Defining Suicide. San Diego: Mentalhelp.net. 2007 Oct 25. Available: <https://www.mentalhelp.net/articles/defining-suicide/> (accessed 2016 Jan 25).
11. Chambaere K, Vander Stichele R, Mortier F, Cohen J, Deliens L. Recent trends in euthanasia and other end-of-life practices in Belgium. *N Engl J Med*. 2015; 372 (12): 1179-1181.
12. Oregon Public Health Division. Oregon's Death with Dignity Act 2014 Annual report. Oregon Health Authority. 2015 December 12. Available: <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> (accessed 2015 November 22).
13. Oregon Public Health Division. Prescription history – Oregon Death with Dignity Act. Oregon Health Authority. Updated 2015 Feb. Available: <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/prescriptionhistory.pdf> (accessed 2015 November 22).
14. Quality end-of-life coalition of Canada and Canadian Hospice Palliative Care Association. The way forward national framework: A roadmap for an integrated palliative approach to care. 2015 March. Available: <http://www.hpcintegration.ca/resources/the-national-framework.aspx> (accessed 2015 December 6).
15. University of Missouri Health System. Second victim trajectory. 2009. Available: <http://www.muhealth.org/app/files/public/1390/6StagesRecovery.pdf> (accessed 2015 November 12).
16. Pratt S, Kenney L, Scott S, RN, Wu A (2012). How to develop a second victim support program: A toolkit for health care organizations. *Jt Comm J Qual Patient Saf* 2012;38 (5):235-40.

17. Dyer O, White C, Rada AG. Assisted dying: law and practice around the world. *BMJ* 2015;351:h4481 doi: 10.1136/bmj.h448.
18. Odell J, Abhyankar R, Malcolm A, Rua A. Conscientious objection in the healing professions: A readers' guide to the ethical and social issues. Scholarworks. Indiana University-Perdue University Indianapolis. 2014. Available: <https://scholarworks.iupui.edu/bitstream/handle/1805/3929/conscientiousobjectionethicalanalyses.pdf?sequence=1> (accessed 2015 December 12).
19. *The Constitution Act, Schedule B to the Canada Act 1982 (UK), c 11.* (CanLII). Available: <https://www.canlii.org/en/ca/laws/stat/schedule-b-to-the-canada-act-1982-uk-1982-c-11/latest/schedule-b-to-the-canada-act-1982-uk-1982-c-11.html> (accessed 2016 January 10).
20. Lewis-Newby M, Wicclair M, Pope T, Rushton C, Farr C, Diekema D et al. An Official American Thoracic Society Policy Statement: Managing Conscientious Objection in Intensive Care Medicine. *Am J Respir Crit Care Med* 2015; 192(2): 219-227.
21. Local Health System Integration Act, S.O. 2006, c.4 Available: <https://www.ontario.ca/laws/statute/06l04> (accessed 2016 January 20).
22. *An act respecting end-of-life care.* RSQ 2014, c S-32.0001 (CanLII) Available: <http://canlii.ca/t/5290t> (accessed 2016 January 20).
23. *Canada Health Act.* RSC 1985, c.C-6. Government of Canada. Available: <http://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html> (accessed 2016 January 20).
24. Community Ethics Network. Ethics toolkit: Ethical decision-making in the community health and support sector. Toronto Central Community Care Access Centre. Canada; 2008: 1-19.
25. Family Service Toronto. FST Vision, Mission and Values. Toronto. Definition of Family. Available: <http://www.familyserVICEToronto.org/mission.html> (accessed 2015 December 15).
26. Hafferty FW. Beyond curriculum reform: Confronting medicine's hidden curriculum. *Academic Medicine* 1998; 74(4):403-407.
27. Danaher A. Reducing health inequities: Enablers and barriers to inter-sectoral collaboration. Toronto: The Wellesley Institute. June 2011. Available: <http://www.wellesleyinstitute.com/wp-content/uploads/2012/09/Reducing-Health-Inequities-Enablers-and-Barriers-to-Intersectoral-Collaboration.pdf> (accessed 2016 January 20).
28. Canadian Bioethics Society. Association of Practicing Healthcare Ethicists. *Definition of practicing healthcare ethicist.* 2014. Available from <https://www.bioethics.ca/caphe.html> (accessed 2016 January 25).
29. International Bioethics Committee of UNESCO. The principle of respect for human vulnerability and personal integrity. Paris: United Nations Educational, Scientific and Cultural Organization; 2013. Available: <http://unesdoc.unesco.org/images/0021/002194/219494E.pdf>
30. Law Commission of Ontario. Vulnerable workers and precarious work. Toronto: December 2012. Available: <http://www.lco-cdo.org/en/vulnerable-workers-final-report> (accessed 2015 December 15).
31. ten Have H. Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics. *J Bioeth Inq* 2015; 12(3):395-408. Doi: 10.1007/s11673-015-9641-9.
32. College of Occupational Therapists of Ontario. Guide to the code of ethics. 2012 Accessible from: [http://www.coto.org/pdf/publications/Guide\\_to\\_Code\\_of\\_Ethics.pdf](http://www.coto.org/pdf/publications/Guide_to_Code_of_Ethics.pdf) (accessed 2015 December 15).
33. Jacobson N. Dignity and health: a review. *Soc Sci Med* 2007; 64(2):292-302.
34. <http://www.etymonline.com/index.php?term=equity> Accessed 25 October 2015.
35. Gabr M. Health ethics, equity and human dignity. In Mansourian B-P editor. *Global Perspectives in Health Volume 1.* Paris: Eolss publishers; 2009. Available: <http://www.humiliationstudies.org/documents/GabrHealthEthics.pdf>
36. Lolas F.[The bioethics challenge of equity: its significance in public health]. *Revista Española de Salud Pública,* 2001; 75(3):187-92.
37. Upshur R, Faith K, Gibson JL, Thompson AK, Tracy CS, Wilson K and Singer AS. Ethics is an epidemic: ethical considerations in preparedness planning for pandemic influenza. *Health Law Review* 2007; 16(1): 33-9.