

# *After Carter v. Canada:* Physician Assisted Death in Canada

## Report and Recommendations

University of Toronto Joint Centre for Bioethics (JCB)  
Task Force on Physician Assisted Death

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# Table of Contents

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<u>Section</u>	<u>Page</u>
1.0 INTRODUCTION.....	1
2.0 EXECUTIVE SUMMARY .....	2
3.0 BACKGROUND.....	5
3.1. ETHICS PRINCIPLES AND LEGAL CONTEXT .....	4
4.0 KEY FINDINGS AND RECOMMENDATIONS .....	7
4.1. INCLUSION CRITERIA FOR PAD.....	7
4.1.1. REQUEST FROM A CAPABLE ADULT.....	7
4.1.2. THE CONSENT IS CLEAR AND MADE VOLUNTARILY .....	8
4.1.3. THE ILLNESS IS GRIEVOUS AND IRREMIABLE .....	9
4.1.4. THE SUFFERING IS ENDURING AND INTOLERABLE TO THE INDIVIDUAL .....	11
4.2. THE DECISION PROCESS.....	11
4.2.1. A RESPONSIBLE PHYSICIAN WITHIN A COLLABORATIVE TEAM.....	11
4.2.2. FIRST STEPS AND TIMEFRAMES .....	12
4.2.3. AUTONOMY AND RELATIONSHIPS.....	12
4.2.4. CONSULTATIONS .....	13
4.3. INTEGRATION OF PAD INTO END-OF-LIFE CARE .....	13
4.3.1. RECOMMENDATIONS FOR PALLIATIVE AND END OF LIFE CARE .....	15
4.4. CONSCIENTIOUS OBJECTION .....	16
4.4.1. INSTITUTIONAL POLICIES FOR PAD REQUESTS .....	17
4.5. REVIEW AND OVERSIGHT.....	18
4.5.1. PROVINCIAL/TERRITORIAL REVIEW COMMITTEE.....	19
4.5.2. NATIONAL DATA COLLECTION AND MONITORING BODY.....	20
4.5.3. SPECIAL CONSULTATIVE COMMITTEE (LOCAL).....	21
4.6. EDUCATIONAL EFFORTS AND SUPPORT.....	22
5.0 CONCLUDING REMARKS .....	24
6.0 APPENDICES .....	25
6.1. TASK FORCE MEMBERSHIP.....	25
6.2. IDEAL PATIENT AND HEALTH CARE PROVIDER EXPERIENCE.....	27

# 1. Introduction

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On February 6, 2015, the Supreme Court of Canada declared in *Carter v. Canada* that the absolute criminal prohibition of physician-assisted death (PAD) is unconstitutional.<sup>1</sup> The Court specified certain circumstances in which it must be lawful for a person to choose PAD, and gave the federal government one year to enact a legislative response within its jurisdiction, failing which the provision of PAD meeting the Supreme Court of Canada's criteria for eligibility would be ungoverned by the criminal law. The institution of PAD will introduce a profound change into Canada's health care system.

In May 2015, the University of Toronto Joint Centre for Bioethics (JCB) commissioned a Task Force on Physician-Assisted Death (the "Task Force") to clarify the *ethical dimensions and implications* of PAD implementation and provide recommendations to inform the development of PAD policy and practice by policymakers, legislators, and professional groups in Canada. The Task Force was chaired by Dr. Philip Hébert (Professor Emeritus, Department of Family and Community Medicine, University of Toronto) and comprised 14 members from a range of disciplinary and professional backgrounds in ethics, law, medicine and policy. (See 6.1 Task Force Membership.)

In June-October 2015, the Task Force surveyed the academic literature on PAD and reviewed publicly accessible policy documents, position statements, and presentations from Canadian stakeholder organizations (e.g., Canadian Medical Association, Council of Canadians with Disabilities) to identify key issues related to implementation of PAD and to develop ethically sound recommendations to address these issues in practice. A draft of the Task Force report was shared with five independent reviewers with relevant expertise for their comments and feedback before finalizing the report. The views of the participants in this Report are unofficial ones only.

The purpose of this report is to inform continuing policy and practice discussions in Canada about the implementation of PAD. As understanding of PAD evolves, some of our recommendations may be subject to revision. This is a contentious area in health care and so it should be not surprising, given the diversity of views on the topic, that few of the Task Force's recommendations were supported by every Task Force member. In the report, we note the areas of substantive agreement and disagreement. For more information about the Task Force or to share your thoughts on the report, please contact Laurie Bulchak ([laurie.bulchak@utoronto.ca](mailto:laurie.bulchak@utoronto.ca)).

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<sup>1</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5, a unanimous decision of the full Court delivered February 6, 2015, in which they distinguished the earlier decision of a closely divided Court (5-4) in *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519, and declared Sections 241 and 14 of the Criminal Code invalid insofar as they prohibit physician assistance in ending life in certain circumstances.

## 2. Executive Summary

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The overall conclusion of the Task Force is that physician-assisted death (PAD) in Canada ought to begin cautiously, with a well-scrutinized and strongly supported process that promotes equitable access to PAD as one of a comprehensive range of alternatives for responding to suffering and providing end-of-life care. The provision of an effective and compassionate PAD process, as envisioned by the Task Force, will require a tremendous amount of effort and deliberation by health care professionals, patients, politicians, health care administrators, and the public. The Task Force emphasizes that a PAD process, best satisfying the fundamental principles of ethics and meeting the legal requirements set out by the Supreme Court of Canada in the *Carter* decision, cannot be separated from society's obligation to ensure that sufficient resources for palliative and EOL care are available and fairly apportioned to all in Canada.

The Task Force recommends that eligibility for PAD should initially be confined to capable adults who make the request themselves (not by substitute decision-makers or proxies), and who have a grievous and irremediable medical condition causing enduring suffering that is intolerable to them. Although the use of advance medical directives for care is an important way for patients to direct their future care, the Task Force considered it too early to recommend their routine use for PAD decisions. However, to not allow their use would be to treat patients facing severe and irreversible cognitive decline differently from physically incapacitated patients. As more experience is gained with PAD, avenues for integrating it into advanced care directives should be considered. The Task Force was divided about excluding those suffering from a primary mental health or psychiatric disorder, and the report sets out the differing views on this issue. The risk that those fearing exclusion – whether having a psychiatric illness or suffering from an incipient loss of capacity – will seek death earlier by other means must be addressed. This highlights that it is vital in all cases to ensure the best treatments possible for the suffering person. The Task Force recommends re-examining the inclusion and exclusion criteria following an initial experience with PAD after which PAD's impact has been assessed.

Task Force members were generally agreed that the responsibility for PAD should rest with any physician who is willing to assess a PAD request and not be confined to specialists (such as palliative care physicians). There must be clear and effective pathways to ensure that a request made to any health care provider comes to such a willing physician in a way that is timely and effective for the person requesting it. When a PAD request is made, it is an invitation to commence a robust response. While a physician will bear ultimate responsibility for the PAD process in each individual case, a collaborative inter-professional team approach is called for, attuned to the individual's needs and wishes, their relationships, and the full range of treatments and alternatives available to them in their circumstances.

The Task Force recommends a 'stringent' and thorough process in responding to requests for PAD. All cases should require a second opinion from an independent physician. In cases where a psychiatric symptom or condition is a primary diagnosis and may be affecting the person's capacity to make a PAD decision, an independent psychiatric or mental health assessment should be

required. This would not necessarily have to be a physician, but someone qualified to perform complex assessments such as this. Careful and comprehensive documentation must follow such assessments. Disputes about someone's capacity could be managed in a variety of ways, as is done currently – in Ontario, for example, through the Consent and Capacity Board. Elsewhere it could be managed by referral for another opinion or by seeking access to the courts.

An important issue the Task Force discussed was how PAD could be integrated into the health care system in Canada. In the strong view of many members, every dying or irremediably ill person – and not just the dying – should have access to a comprehensive, high quality set of health care services, such as palliative care and exemplary end-of-life (EOL) care. PAD would be simply one part of EOL care. To achieve this, the Task Force recommends a legislated *End-of-Life Bill of Rights* and the rigorous development of a comprehensive, high quality, EOL care structure. Strong concern was expressed by the Task Force that efforts to integrate PAD into EOL care should not undermine efforts to improve and strengthen palliative care in Canada today. The Task Force also considered where PAD ought to be provided. Acute care hospitals are less than ideal places for elective deaths. Most people want to die at home. This should be possible but may not be if the patient is homeless, lives alone, or is too ill to be moved. The Task Force recommends consideration of a designated subset of publicly funded health institutions that would meet the needs of this small population of patients. Just where and how they would be distributed would be a decision that would have to be made at provincial and federal levels in the light of experience with PAD.

All Task Force members agreed that physicians and indeed all health care professionals ought to have the right not to take part in a process to which they have a conscientious objection. However, there was considerable Task Force discussion about how best to ensure the recognition and exploration of a patient's request for PAD in the face of an objecting physician's conscience. Key questions were: Is there a duty to refer? Is there a duty to transfer the patient to another physician or health care provider? What would these duties look like?

Many Task Force members were of the view that a conscientiously objecting physician must provide an 'effective referral' to a willing physician. This meant different things to different people. Some felt it would suffice to, minimally, provide the patient with 'contact information' or a phone number for a service providing such referrals. Others were concerned that such a service did not yet exist and that contact information alone would not work for all patients. For some this meant the referring physician might have to refer the patient to a *willing* practitioner (defined as being trained and capable in this area *and* prepared to fairly assess the patient's suitability for PAD and willing to participate in it) and so implicate the referring physician more deeply into the PAD process. Some preferred a duty to refer, although this would sometimes be unnecessary and unpleasant for objectors, while others preferred a duty to inform, even if this might not always be sufficient to ensure access for patients. Yet others thought that the refusing physician should take all the necessary steps required and *transfer* the patient to a willing MD—which would include providing a full consultation note and an explanation of the need for services. The report sets out the diverging viewpoints and rationales, along with an optimistic attempt at a solution in a recommended set of policies for responding to PAD requests. The concern is not just effective

referral but *effective access* to services by patients. (See 6.2 for a diagrammatic representation of the 'Ideal Patient and Healthcare Provider Experience'.)

The Task Force recommends that all institutions have well-developed policies as to how they will manage and meet patient expectations. There are, however, unresolved issues raising ethical concerns about access to PAD in different institutions that must be addressed by attention at a systems-wide (provincial, federal) level. Not every health care institution needs to, or should, offer PAD but all need to have a system in place that ensures their patients are aware of and have effective access to all EOL options feasible for them, including PAD, and these must be shared across institutions. Those institutions that do decide to offer PAD ought to consider the unique needs of dying patients and try to accommodate them by special rooms and identify appropriately trained and committed staff.

The Task Force believes that new mechanisms will need to be put in place to scrupulously ensure best practice in PAD. There should be mandatory provincial and federal bodies for retrospective review and oversight, and opportunities to revisit the practice of PAD after experience is gained and relevant information gathered and analyzed. The Report recommends structures and mandates for these mechanisms, in proposing Special Consultative Committees locally (referred to above as part of the stringent process), a Provincial / Territorial Review Committee, and a National Data Collection and Monitoring Agency. Only certain cases, but not all, will require prospective or antegrade review and these are also discussed in the Report.

It also believes that educating health care professionals and the public about this new element of practice is critically important. The necessary training of all health care professionals who will engage in PAD, and the necessary supports for them, must be identified and provided by their schools, associations, organizations, and institutions. The public must also be provided with the information and resources necessary to understand and work well with the PAD process, and thus support and strengthen it.

## 3. BACKGROUND

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### 3.1. Ethics Principles and Legal Context

PAD is the practice of consciously and openly helping grievously and irremediably ill capable adults who wish to end their lives – early, hastened – with the assistance of a physician. (We here use the terms the Supreme Court used, referring to a physician ‘assisting’ at – aiding or hastening or effecting – a patient’s death.) No one should feel entirely certain and comfortable concerning this complex moral issue and evolving medical practice, especially in a pluralistic society. PAD should be considered as an option of last resort when other, less ethically challenging, alternatives have been exhausted, failed, or are considered unsatisfactory by the individual. A request for a hastened death may be the preferred choice for a minority of people over the other options they have.

Underlying this document are the important ethical principles and core ethical values of the modern health care professional and of society more generally. The principles of patient self-determination and privacy, critical to the contemporary notion of autonomy – must be considered along with the principles of beneficence (promoting the good) and non-maleficence (preventing harm). These principles cannot be defined by the medical profession alone but must reflect, where possible, the beliefs and values of patients. As well, patients must be better, and not worse off, on account of a medical intervention such as PAD. *This means that an assisted or hastened death, with a physician’s involvement, must be better for, and wanted by, patients in certain situations.* ‘Better’ here means, not in the eyes of others, but in the eyes of the requesting patient alone. This would rule out support for any form of non-voluntary or third party requests for a hastened death for an affected individual. The principles of fairness and equity; principles must also be considered in decisions about the provision of palliative care and good end-of-life (EOL) care. All of these principles, including considerations of health professional virtues (e.g., compassion), have informed the deliberations behind this report.

The Task Force examined the ethics principles relating to PAD within the legal framework established by the Supreme Court Canada in its *Carter* decision. The Court held that the blanket prohibition of PAD violates the individual’s right to life, liberty, and security of the person. This includes the right to make ‘fundamental personal choices’ about our ‘own fate’, our ‘bodily integrity’, our ‘medical care’, and our ‘passage to death’, free from unjust state interference.<sup>2</sup> In ‘certain circumstances, an individual’s choice about the end of her life is entitled to respect’.<sup>3</sup> Those circumstances are where ‘a competent adult’ who ‘clearly consents’ has ‘a grievous and irremediable medical condition’ that causes ‘enduring suffering that is intolerable to the individual’.<sup>4</sup> ‘Irremediable’, the Court specified, ‘does not require the patient to undertake treatments that are not acceptable to the individual.’<sup>5</sup>

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<sup>2</sup> *Carter, id.*, paras 63-67

<sup>3</sup> *Carter, supra* note 1, para 63

<sup>4</sup> *Carter, supra* note 1, para 4

<sup>5</sup> *Carter, supra* note 1, paras 127

Safeguards are necessary ‘to protect vulnerable persons from being induced to commit suicide at a moment of weakness’, the Court held, noting the risks to vulnerable people of being subject to ‘abuse and error’ – coercion, undue influence, ambivalence, and not being properly informed of their diagnosis, prognosis, and treatment options, including palliative care.<sup>6</sup> These risks ‘arise in all end-of-life medical decision-making’, and assessing a vulnerable person’s decisional capacity is ‘already part and parcel of our medical care system’.<sup>7</sup> To make these assessments in the PAD context requires a scrupulous system:<sup>8</sup>

The trial judge ... concluded that the risks of physician-assisted death ‘can be identified and very substantially minimized through a carefully-designed system’ that imposes strict limits that are scrupulously monitored and enforced. ... We agree with the trial judge that the risks associated with physician-assisted death can be limited through a carefully designed and monitored system of safeguards.

The Court expressly confined its declaration to ‘the factual circumstances of this case’, stating: ‘We make no pronouncement on other situations where physician-assisted dying may be sought.’<sup>9</sup> The case involved two adults diagnosed with incurable medical conditions, both physical illnesses (one a fatal neurodegenerative disease and the other a severe osteoarthritis of the spine), and both having deteriorated to the point of rendering the person wheelchair-bound, in pain, and requiring support for daily life functions.<sup>10</sup> While the Court addressed ‘the rights of those who seek assistance in dying, rather than those who might provide such assistance’, it noted the right of physicians to freedom of conscience and religion, and underlined that ‘the Charter rights of patients and physicians will need to be reconciled.’<sup>11</sup> The Court noted that PAD is a matter of concurrent provincial (health) and federal (criminal law) jurisdiction, and that regulating PAD involves weighing competing social values and perspectives, and is open to ‘a number of possible solutions’.<sup>12</sup>

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<sup>6</sup> *Carter*, *supra* note 1, paras 27, 86, 105, 107, identifying ‘the elderly’, ‘disabled’, and ‘socially vulnerable populations’; the risks of PAD argued at trial included failures in detecting and errors in assessing ‘cognitive impairment, depression or other mental illness, coercion, undue influence, psychological or emotional manipulation, systemic prejudice (against the elderly or people with disabilities), and the possibility of ambivalence or misdiagnosis’: para 114

<sup>7</sup> *Carter*, *supra* note 1, paras 104-05, 107, 120; the Court accepted the trial judge’s conclusions on the evidence that PAD would not have an ‘inordinate impact’ on vulnerable people, or result in ‘a slippery slope, leading to the casual termination of life’, or be distorted by ‘unconscious bias by physicians’, or that physicians would be unable to ‘reliably assess competence, voluntariness, and non-ambivalence in patients’ or to ‘understand or apply the informed consent requirement’ in the PAD context. The trial judge also noted evidence from permissive jurisdictions showing that ‘in some cases palliative care actually improved post-legalization’ and ‘physicians were better able to provide overall end-of-life treatment once assisted death was legalized’: para 107

<sup>8</sup> *Carter*, *supra* note 1, paras 27 and 107 (for quote set out), 29, 105, 115-17

<sup>9</sup> *Carter*, *supra* note 1, paras 69, 127

<sup>10</sup> *Carter*, *supra* note 1, paras 11, 12, 17, 29, 86: Gloria Taylor suffered from amyotrophic lateral sclerosis, or ALS (causing progressive muscle loss and eventually the inability to move, swallow, or breathe), and Kathleen Carter suffered from spinal stenosis (causing progressive compression of the spine).

<sup>11</sup> *Carter*, *supra* note 1, paras 130-32

<sup>12</sup> *Carter*, *supra* note 1, paras 53, 97, 98, 125, 128, 132



## 4. Key Findings and Recommendations

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### 4.1. Inclusion Criteria for PAD

The Supreme Court outlined the following four circumstances that justify an individual being considered for physician assistance at death:

- The request is made by a capable adult;
- The consent is clear and made voluntarily;
- The illness, disease, or disability is grievous and irremediable;
- The suffering is enduring and intolerable to the individual.

#### 4.1.1. REQUEST FROM A CAPABLE ADULT

In keeping with the caution in implementation, it would be most appropriate to initially allow requests only from adult, capable individuals themselves – not from minors, and not from a substitute decision-maker or a proxy. In other words, requests must be ones made by capable adults. If advance directives are to be taken into account, they must be made ‘clearly and voluntarily’, and it must be stringently ensured that the directive and the request meet the criteria required. Just who is an ‘adult’ was not defined by the Supreme Court; since it can mean different things in different legal and regulatory contexts, this raises important questions as to when, by what age, and how persons of younger age might be allowed access to consideration for a hastened death.

With respect to minors or children, cases can be envisioned where a blanket exclusion by age alone seems unethical. Some children face circumstances and have a wisdom that is beyond their chronological years. Current Ontario law permits and judicial precedent allows minors to make their own treatment decisions if they are capable, without regard to age. While the Task Force concurs with the Court that PAD be restricted to adults,<sup>13</sup> restricting access on the basis of age alone – be it 14, 16, or 18-years-of age – would be to set an arbitrary limit. What is important is the capacity and freedom of the person making a decision: can they understand and appreciate the decision about PAD and can they do so not under the undue influence of others? The younger the patient, the more that the implications of their age must be taken into account in the careful and comprehensive the assessment of their capacity.

However, the assessment of young people for competence in this area is fraught with uncertainty. It requires appropriate processes to be established and evaluated, as experience and trust are gained in assessing requests for PAD, before the eligibility of minors for a hastened death can be contemplated. In the meantime, healthcare professionals should use other means, such as the most effective palliative care, including palliative sedation, to address the suffering of minors. Indeed, the same approach to mitigating suffering by palliation and good EOL care should be offered to all persons, young and old.

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<sup>13</sup> *Carter, supra* note 1, para 111

With respect to incapable adults, there is a distinction to be made between deciding for another that PAD is appropriate and following the advance directive of a now incapable person. The problem with allowing ‘proxy’ or substitute decision-making in this area is the difficulty in appreciating the suffering being experienced by a person with diminished consciousness or by an incapable person. A related problem in each circumstance is the difficulty of objectively assessing the present status of a prior expressed wish for PAD. Advance care planning documents might only imperfectly reflect the wishes of individuals and might unreliably predict how they will rate their quality of life in a future state of decline and disability when they are in that state. So, when it comes to advance directives for a hastened death, caution must be exercised in their use.

The issue of advance directives for PAD was not considered in the Supreme Court’s ruling but is clearly an important one. There are two problems with not allowing advance directives PAD for care to be followed. One is that it may cause people, fearing of a loss of their capacity before a PAD request can be acted upon, to seek access to PAD or to attempt suicide prematurely. Second, if their directives are not acted on and they lose their mental capacity, they will be forced to endure circumstances under which they would not have chosen to live. This is akin to the problem, addressed by the Court in the *Carter* decision, of the fear of physical (rather than mental) incapacity leading people to end their lives earlier than they otherwise wished. This concern could arise whenever a person fears their request for PAD will be denied.

#### 4.1.2. THE CONSENT IS CLEAR AND MADE VOLUNTARILY

There are concerns that informed consent may be difficult to assess or abide by in some cases. Individuals may feel an obligation to seek PAD if they perceive themselves as a burden to their families or society, for example.

Capacity is typically understood as the individual’s ability to understand the nature of a decision and to appreciate its consequences. The difficulty of assessing the capacity to request assistance in dying, particularly in the context of individuals with psychiatric conditions, was a challenge identified by Task Force members. However, there is no evidence of a significant difference between assessing capacity for PAD and assessing capacity for such other medical decisions as withdrawal of life-sustaining treatment, which is also a complex assessment and one that is an everyday decision for some health care providers. As well, capacity is issue-specific, both legally and practically. It is wrong to assume a person incapable of making treatment decisions respecting a mental disorder is *ipso facto* incapable to make a PAD decision, whether or not the intolerable condition is the mental disorder.

Processes must be in place to prevent vulnerable individuals from feeling or being coerced and to ensure that individuals who request PAD are fully informed of the nature of their decision, the risks and benefits, and all the alternatives and their likely consequences. The Supreme Court stressed that ‘a properly administered regulatory regime’– one that is ‘carefully designed’ and ‘stringently monitored’– is ‘capable of protecting the vulnerable from abuse or error’, and is required in order

to minimize the risks to them.<sup>14</sup> Later in this Report, under heading 5, the Task Force proposes a regulatory scheme for fulfilling this crucial requirement.

The Task Force members were also of the opinion that having a psychiatric condition did not necessarily mean that an individual would be incapable of making a decision about PAD. Additionally, many were concerned that excluding individuals suffering from mental health or psychiatric conditions was not only indefensible ethically and factually, but might also violate their Charter equality rights – thus necessitating lengthy court proceedings on their behalf to ultimately reverse what might well be an unjustified limitation of eligibility.

#### 4.1.3. THE ILLNESS IS GRIEVOUS AND IRREMEDEABLE

Whether an illness is grievous and irremediable may not be easy to determine. Nowhere in the Supreme Court decision is there the requirement that an individual have a terminal or even a physical illness. It also does not state that the individual must have exhausted all therapeutic options, although it is clear the Court had in mind very ill individuals – those, for example, with end-stage cancer or in the later stages of ALS. The Supreme Court did find that PAD was acceptable even in the case of severe osteoarthritis or spinal stenosis where the individual was immobile and in constant pain, as was the case for Kathleen Carter, whose daughter, Lee, was one of the plaintiffs in the *Carter* case.

The idea that suffering individuals need not be terminally ill or imminently dying to be considered eligible for PAD was a concern to some members of the Task Force. Just when should a person be eligible for PAD is a serious matter and calls for especially careful review if the patient is not dying. It should never be seen as a quick or easy solution to the complicated lives of desperately ill patients who may want to speed up their dying for a variety of reasons — some that are good for them, some that are not. They may want to pre-empt an imminent and painful demise, or to mitigate the suffering of others watching them die; they may do it out of fear, or out of loneliness and social isolation. This is a vital part of the professional assessment of eligibility for PAD that must be considered in guidelines and in educational efforts aimed at the public and the profession.

The Task Force was mindful that just because one physician or institution was unable to successfully treat an individual does not mean that the individual's condition is untreatable. At the same time, as the Supreme Court stated with respect to the PAD context, the decision as to whether a condition is 'irremediable' is a matter of values – not only medical judgment but also patient acceptance or choice of treatment options. As capable individuals have the right to refuse to consent for a proposed treatment, the Task Force did not consider it necessary, following the Court's ruling, that an individual to be eligible for PAD would have had to avail themselves of all possible treatments. The Supreme Court would not require undertaking treatments that are not acceptable to a capable adult (e.g., Jehovah's Witnesses patients who would refuse blood transfusions for themselves on grounds of religious belief or personal values).

The Task Force also debated the eligibility of PAD for individuals suffering with psychiatric conditions. Patients suffering from acute suicidal impulses on account of depression or psychosis would clearly not meet the Court's criteria. Some members were of the view, however, that

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<sup>14</sup> *Carter*, *supra* note 1, para 3; *see also* paras 27, 105, 117

treatment-resistant major depression and some other psychiatric conditions could meet the test of being a 'grievous and irremediable medical condition'. People can experience intolerable suffering associated with some psychiatric conditions. These members saw no reason in principle or logic why individuals with such mental health conditions could not qualify for PAD if their illness was both grievous and irremediable and their suffering both enduring and intolerable.

Even in these days of medical miracles, continuing limitations in our existing ability to treat certain illnesses – including some psychiatric disorders -- and to ameliorate all psychological suffering must be acknowledged. The availability of PAD could have beneficial effects for such patients, such as encouraging honest and open communications about the desire to end one's life, and spurring the development of more effective and accessible treatments and other supports that reduce their suffering.

Other members of the Task Force held the strong view that offering PAD to individuals with a serious psychiatric disorder as their primary diagnosis would never be appropriate. These members felt that there are effective treatments available for grievously ill individuals with psychiatric conditions which make the option of PAD unnecessary and, at times, counterproductive to best medical efforts at helping to ameliorate and improve the outcomes and lives of these individuals. They also considered that PAD could go too far, in particular for psychological illnesses, in attempting to eliminate suffering from ordinary human life rather than finding or accepting supports for enduring it.

For the majority of the Task Force members, psychiatric illness would not in itself be an appropriate exclusion criterion for eligibility for PAD, but, as in all cases of enduring and intolerable suffering from a grievous and irremediable medical condition, an occasion for a robust health care response. The difficulty is that serious but treatable psychiatric disorders might be irremediable only because the individuals refuse treatment. They have the right to do this, but they would have to find a willing doctor to gain access to PAD. As no doctor is obliged to help a patient seeking PAD, these individuals would no doubt make up, as in other jurisdictions, a significant proportion of those refused access to duly authorized PAD, and those for whom it is important to provide exemplary alternative treatments. How individuals with serious psychiatric illnesses should be best evaluated with respect to their eligibility for PAD remains a question to be revisited in light of further experience.

Individuals who seek PAD as a result of their psychiatric condition *and* where that condition undermines their capacity for decision-making, as determined by standard defensible methods, should not be eligible for PAD in Canada. Indeed, 'capacity' is one of the Supreme Court's criteria to be considered in determining a person's eligibility for PAD. Assessments of a person's capacity to make such EOL decisions could be made not only by physicians but by or with the assistance of a special class of 'capacity assessors' properly qualified to make or assist in the complex assessments required. If an individual is denied access to consideration for PAD, on the grounds of irremediable nature of their illness, this Report recommends access to the Consultative Committee (see below) that could provide advice as to how to best proceed and what options there might be. (If the patient's capacity is at issue, patients and physicians in Ontario have access to the Consent and Capacity Board; however, this is not an option anywhere else in Canada.)

#### 4.1.4. THE SUFFERING IS ENDURING AND INTOLERABLE TO THE INDIVIDUAL

Suffering is an individual experience and inherently subjective. In some cases, over time a person comes to accept and accommodate to a change in their condition, even when the change is catastrophic, as in serious spinal cord injury cases. In other cases, however, in similar medical conditions, personal acceptance and accommodation seem to never occur and intolerable suffering endures. While it is difficult to assess another person's subjective experience of 'intolerability' of their suffering, this type of assessment is not unique to EOL care or to the practice of PAD.

How we tolerate our own suffering and that of others is a major preoccupation, for example, in palliative care medicine. Patients often have a depressed mood when they are dying and when they are grievously ill. That does not mean that depression and other psychiatric conditions are normal or an inevitable response to dying.<sup>15</sup> These conditions are often treatable.<sup>16</sup> Many wishes for hastened death – as with suicidal impulses generally -- are transient.<sup>17</sup>

To recognize and abide by the wishes and preferences of patients and to mitigate their suffering are the two fundamental standards of palliative care and EOL care. Every physician concerned with treating patients at life's end undertakes to ease their deaths, to put their comfort and quality of life ahead of quantity as a patient desires it, responding to their experiences of suffering and relief, and to provide only the care that patients want. One factor that helps many people shoulder suffering is having some measure of control over their dying. Knowing the option of PAD exists may be comforting for some people even if they never use it.

## 4.2. The Decision Process

### 4.2.1. A RESPONSIBLE PHYSICIAN WITHIN A COLLABORATIVE TEAM

A team approach is called for in the PAD context – an inter-professional team, collaborating in a circle of care for the grievously ill individual, working together to develop an in-depth and 360-degree view of the individual. The willing physician (defined as being trained and capable in this area *and* prepared to fairly assess the patient's suitability for PAD *and* willing to participate in it), who has the ultimate responsibility for the PAD act, and for ensuring the proper conditions are met, should not be seen as a solo actor, but rather as someone acting in collaboration with other professionals. The team must not limit its focus to the PAD act, but attend to the individual's whole journey of suffering, living, and dying. The alternatives and the range of treatments must be taken into account, and, in addition to the individual's needs and wishes, their relationships and supports, and the possibility for them to develop different perspectives and make choices other than ending their life through death hastening care.

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<sup>15</sup> Miovec M, Block S, Psychiatric disorders in advanced cancer. *Cancer* 2007; 110: 1665-1776.

<sup>16</sup> Block S, ACIP-ASIM End-of-Life Care Consensus Panel. Assessing and managing depression in the terminally ill. *Ann Intern Med* 2000; 132: 209-218.

<sup>17</sup> Emanuel E, Fairclough D, Emanuel L, Attitudes and desires related to euthanasia and physician-assisted-suicide among terminally ill patients and their caregivers. *JAMA* 2000; 284: 2460-68.

#### 4.2.2. FIRST STEPS AND TIMEFRAMES

The Task Force considered what the first steps should be following a request for PAD, and what ‘standard of reasonable care and skill’ should be established for the practice of PAD. This Report is intended to provide the rationale for and the framework of an ideal ethical practice in responding to a request for PAD. This Report will not examine the various legal schemata that have been well written and proposed in this area. All of these detail the requirements of witnessed requests made in writing, usually made at appropriate intervals, ensuring the patient’s informed capacity, and so on. This Report will concentrate on the ethical issues raised. (See 6.2 Ideal Patient and Provider Experience.)

*When a PAD request is made, it is an invitation for a thorough response.* It is not a matter of simply waiting for repeat requests, or providing patients with a telephone number or Internet link regardless of their circumstances. Respect for persons and the principle of patient autonomy call for immediate attention to the patient’s request. Open communication and discussion of the patient’s beliefs, values, and condition are essential and must be done promptly. Beneficence requires non-abandonment and a robust initial response by health care practitioners – treating the request as a cry for help and an opportunity to open up a conversation about the person’s suffering, medical condition, and treatment options.

Any recommended time frames (e.g., the recommended delay between two requests for PAD) should be treated as guidelines subject to ethical review, medical realities, and individual suffering. In some cases, the medical condition and suffering might call out for a swift response, and time will be of the essence. In others, it might be important not to rush the process, and give the person time to carefully consider their wishes and allow an opportunity for a change of mind. The time required for the evaluation of a request for PAD should be proportional to the anticipated loss of life and not depend on the degree of suffering alone. (Thus, mandating a period of two weeks between requests may be too long an interval for some imminently dying patients.) Although unrelieved suffering may be the prompt for PAD, it may also be the prompt for the involvement of others, such as pain management experts, to ease the patient’s suffering.

#### 4.2.3. AUTONOMY AND RELATIONSHIPS

The Task Force considered the relational dimension and welfare of others and how to balance these alongside the autonomy and dignity of the individual. The Task Force felt it was not an isolated question of the individual’s autonomy, personal choice, and rights. There is also a relational dimension to health care that cannot be ignored and should be addressed with the patient as an important ethical factor. An individual’s decision to request PAD affects not only them: It also affects others, such as, of course, the individual’s family, friends, and those in a person’s circle of care. In the troubling situation of an individual who does not want to engage or inform family and friends about their request for PAD, health care providers must fully explore with the individual their rationale for keeping this secret, and consider appropriate consultations.

An individual’s request for secrecy must prompt a thorough review of his or her circumstances. To simply go along with such requests, would seem, *prima facie*, to be inadvisable. Empathic exploration with the patient should take place. Ultimately, the patient’s right to privacy must be

respected. It is the patient's care and comfort at the close of life that must be the focus of concern. It must be remembered, of course, that not all patients have relatives or friends and their isolation and this lack of supports need to be taken into account concerning decisions about PAD.

#### 4.2.4. CONSULTATIONS

The majority of the Task Force agreed that seeking a second opinion by an independent physician would be appropriate in all cases of requests for PAD to affirm the patient's suitability for consideration for PAD under the *Carter* criteria. Similarly, it was agreed that all cases should be carefully and comprehensively documented and retrospectively reviewed (discussed in detail below in 4.5 Review and Oversight). The Task Force decided that it would be unnecessarily intrusive, cumbersome, and time-consuming to require pre-authorization by a standing tribunal or *ad hoc* committee for every PAD request.

As well, to require a psychiatric consultation in all cases before deciding on a request for PAD was agreed to be overly onerous, too obstructive of patient autonomy, and the benefits unclear in all cases, so that it could not be adequately justified as a requirement in all cases. Some members were concerned about questions of funding, allocation of scarce resources, and the availability and accessibility of appropriate consultants respecting mental health or psychiatric conditions and symptoms manifesting at the closure of life. Others were concerned that requiring a psychiatric consultation sends a message that everyone who requests PAD is suffering from a mental illness. Such a requirement could also unduly delay access to PAD, potentially causing individuals to endure further suffering.

### 4.3. Integration of PAD into End-of-Life Care

The Task Force considered how an individual would gain access to the consideration for PAD services and, it was recognized, there may be a number of access points. It also examined the question as to whom the request should be made – must it be to a physician? If so, would any physician do? Should it be a palliative care specialist or a psychiatrist? It was generally agreed that to respond to an individual's request for PAD, physicians must become involved at *some* point early in the process. Task Force members felt that the response could start out as the responsibility of any physician in the whole profession to whom a request is made. This would not necessarily require the active involvement of each and every physician to whom a request is made, but would require the steps to be taken to bring the request into the PAD process. Here, we draw a distinction between a physician providing access to the PAD process and a physician assessing, responding to, or fulfilling that request.

The Task Force recognized that requests for PAD may come to the attention of a variety of health care providers and that processes need to be in place to help the health care provider respond appropriately to such requests. Every health care provider working in EOL care must know how to ensure that a request to hasten death is compassionately and effectively explored. This is not an optional skill. In other jurisdictions the use of palliative care appears to have increased dramatically in the wake of legalizing PAD. Canada has an existing, but under-resourced, palliative care system. Palliative care in Canada is already overburdened and it cannot be assumed that increased



spending on palliative care will happen automatically. So PAD should not be made the responsibility of palliative care specialists, certainly not when the PAD system is first being established. Whether an increase in palliative care will occur in the Canadian context is unknown. There is a societal obligation to ensure sufficient resources for palliative care are available and fairly apportioned; otherwise, ethical, equitable, and effective EOL care will not be possible.

As for where PAD should take place, it was recognized that acute care hospitals are not the best place for elective deaths. The palliative care system has established hospices and home visiting for patients at the end of life. Hospices or palliative care facilities would be ideal places, as they tend to be quite warm and homelike, and their staff is specially trained in end-of-life care. There is also a reassurance that nothing more to further prolong life, ultimately in accordance with the patient's perspective, will be done. However, many hospices and palliative care physicians do not want at this time to be involved with PAD.<sup>18</sup> Realistically, this opposition must be acknowledged and recognized as a reasonable position to take. This leaves fewer resources for patients: there could be hospitals with willing physicians offering this service in special rooms (much as they do for birthing) or there could be special free standing public facilities dedicated to this purpose and staffed by qualified health care professionals. Given the low numbers of patients likely to seek this service at any one time (see calculations in end note <sup>19</sup>), there would not need to be many of these facilities in Canada. The Task Force was mindful that most patients would want die in their home. However, not all patients have a home or family. Others might be too sick or fragile to leave the hospital or a long-term care institution. Hence, the need for every hospital to have a policy as to how it will manage requests for PAD. Among other things it must identify willing practitioners and establish guidelines around training, qualifications, and the supports needed for practitioners involved in this area.

The Task Force recommends a focus on universal choice, rather than focusing on universal access to PAD alone, at the EOL. This means that every dying or irremediably ill Canadian should be able to have reasonable access to PAD, but as part of a comprehensive high quality EOL care set of services. All stakeholders should play a role in supporting a system of comprehensive EOL care whether or not they support PAD. Experiences locally, provincially, and nationally will be important learning resources for the health care professions and for building capacity in this area. The Task Force recognizes the challenges that exist at a national level to obtaining adequate EOL care. Some European countries have mobile units, but the distances in Europe are many orders of magnitude less than the distances in Canada. A national EOL care strategy, specific to Canada's unique

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<sup>18</sup> Two alternative treatments sometimes offered dying patients, namely 'voluntarily stopping eating and drinking' and 'continuous palliative sedation', can be discussed with individuals but cannot replace PAD and each would be appropriate only when preferred by the dying patient.

<sup>19</sup> Here are some rough calculations: In Canada 700 people die daily in a population of 35 million. Research suggests a rate of hastened death between 0.1% and 3% of all deaths. So, in Canada,

0.1 % = .7 people daily  
3% = 21

In Toronto with 2.6 million, this works out to:

0.1% = 0.0052 or 5 people every roughly 3 months or 1 person every 20 days  
3% = 1.56 people daily



geography and medical system, that encompasses palliative care and PAD is required, which would make this aspect of EOL care a combined federal and provincial / territorial responsibility. Pessimism about the possibility of such cooperation cannot justify inaction.

Palliative medicine, in general, accepts death and fosters an acceptance of death as a part of life. This careful obedience to the needs and wishes of the dying has led to a greater cultural understanding of death. Death is not the enemy for palliative care -- dying poorly is. Indeed, *living* poorly with illness is also a concern for palliative care, and its focus is thus not solely on end-of-life care. Palliative care does not intentionally aim for the patient's death, however, but it accepts death as a risk of symptom management. According to the Canadian Hospice Palliative Care Association, "Hospice palliative care aims to relieve suffering and improve the quality of living and dying." In 2005, that Association released an important report, *The National Framework: A Roadmap for an Integrated Palliative Approach to Care*<sup>20</sup>, on a future plan for palliative care in Canada. It has yet to be implemented. It needs to be an important focus for all levels of government if we are to properly introduce PAD into medicine and ensure it does not end up as a 'default' for the absence of palliative care. We do not want to see patients opting for PAD because they cannot get good palliative care.

Easing death at life's end is also the aim of PAD, which becomes one further way of achieving the goal of providing high quality EOL care. The most satisfactory way forward for many on the Task Force was to recommend the integration of PAD into existing structures of EOL care. But it was also recognized that this may not be possible at this time given the distinction between PAD and palliative care as regards EOL and given the anticipated high rate of conscientious objection among the professionals in the palliative care community. Admittedly, PAD consciously aims at, prepares for, hastens, and causes, the patient's death with the aid of a physician. However, an individual who considers PAD is not necessarily committed to undergoing PAD. It is an option for patients that they need not exercise. In other jurisdictions where PAD is allowed, many more patients seek PAD than are determined to be eligible for it, and more patients are granted PAD than eventually make use of it.

The adoption of PAD highlights and reinforces society's need and obligation to ensure that sufficient resources for palliative care and other alternative treatments are available and fairly apportioned. Governments must be prepared for this. Alternative treatments and supports for suffering must be adequately developed and fairly provided, and individuals must be well informed.

#### 4.3.1. RECOMMENDATIONS FOR PALLIATIVE AND END OF LIFE CARE

- **An-End-of-Life Bill of Rights:** following the lead of Québec in this area, Federal and Provincial governments should enact legislation establishing access to high-quality EOL care (including both comprehensive palliative care and PAD) as a right.

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<sup>20</sup> *The National Framework: A Roadmap for an Integrated Palliative Approach to Care*, report of the "Aller Avant – The Way Forward" initiative, Canadian Hospice Palliative Care Association website, URL accessed Oct 22, 2015: <http://www.hpcintegration.ca/resources/the-national-framework.aspx>

- o Health authorities at all levels need to create EOL benchmarks and quality metrics that must be attained. These must be publicly visible, and organizations should be made accountable for their performance.
  - o Every health region must have identifiable EOL resources, either for consultative or primary care.
- Education and Referral resources for individuals, family members, and health care professionals
  - o Clearly outline EOL services, the availability of PAD, the laws/regulations governing them, and the means of obtaining them. An example would be a website and hotline that could answer questions and arrange referrals for individuals, physicians and family members.
- Provincial and territorial governments must create visible, easy-to-use mechanisms to help individuals and family members advocate for their EOL needs.
- Provincial and territorial offices, either of the regulatory authorities or the professional associations, must provide appropriate supports for, and reviews of, health care professionals involved in this sensitive area.

#### 4.4. Conscientious Objection

As the Supreme Court of Canada recognized, physicians do have and should have the right to refuse to provide PAD as a matter of freedom of conscience and religion. Nurses and other health care professionals involved in PAD must have this right as well, although just how will depend on guidelines issued by their respective colleges and regulatory authorities. In the case of a physician's conscientious objection<sup>21</sup> a distinction was made by some Task Force members between 'informing' a patient about how to obtain PAD from another provider (followed by a transfer of the patient, once he/she has found another provider) and an 'effective referral' of a patient to a willing provider. The effective referral of a patient seemed more morally onerous to some on the Task Force, as it might be seen by some conscientiously objecting physicians as requiring active facilitation of the chain of events that results in PAD, thus implicating them in the act itself.

The College of Physicians and Surgeons of Ontario (CPSO) has commented generally on the duty to refer in its policy on *Professional Obligations and Human Rights*:

Where physicians are unwilling to provide certain elements of care for reasons of conscience or religion, an effective referral to another health-care provider must be provided to the patient. An effective referral means a referral made in good faith, to a non-objecting, available, and accessible physician, other health-care professional, or agency. The referral must be made in a timely manner to allow patients to access care. Patients must not be exposed to adverse clinical outcomes due to a delayed referral.

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<sup>21</sup> By conscientious objection we refer to the firm and fixed personal opinion based on the deepest held moral or religious values or convictions of the individual. As said in another context, such convictions are not subject to the 'transitory standards of the day'. As Donnelly J. put it in *Malette v. Shulman* (1990), 72 OR (2d) 417 (C.A.): "If objection to treatment is on a religious basis, this does not permit the scrutiny of 'reasonableness' which is a transitory standard dependent on the norms of the day." Although stated in the context of a patient refusing treatment, this would also apply to physician objection on the ground of religion or conscience to offering contested care.

Physicians must not impede access to care for existing patients, or those seeking to become patients.<sup>22</sup>

This policy does not explicitly address the issue of PAD as it was approved prior to *Carter*. Task Force members agreed that the conscience rights of practitioners need to be respected in the PAD context, and at the same time that an individual's access to an appropriate form of care should not be frustrated or impeded due to conscientious objections. While the development of the Internet might improve public access to medical care, many patients and family members lack facility with this method of communication, and may be unfamiliar with the concept of self-referral. Furthermore, in our present EOL system, even internet-savvy physicians may struggle to find a willing provider, making it difficult to imagine how a dying or suffering patient might be able to navigate such a system.

If we want to ensure that conscientious objection does not become effectively a barrier to access, we cannot define the duty of the physician in terms of a single action (either informing or referring). The duty must be proportionate to the need of the patient in their situation, which involves a consideration of illness, function, social support, and infrastructure. It could range from information provision to patient referral followed by transfer. An effective referral occurs when the referring physician finds a willing physician capable of accepting the patient and the referral is wanted by, and meets the needs of, the patient in a timely and safe way. If governments and professional organizations want to reduce the burden on individual physicians, they need to create a robust and highly visible system for self-referral that all potential patients can access and use effectively. When such a system is built and ubiquitous, and patients are empowered, the need for formal referral could become minimal to none. But it would be wrong to assume that the same action would protect the right of access in every situation. It is important that the patient's needs be attended to until replacement/alternative care is found, whenever a physician finds a patient's request for PAD so objectionable that he / she can no longer act as the patient's doctor.

Whether health care institutions, insofar as they are publicly funded, have the same right of conscientious objection requires careful attention. There was a consensus that institutions are not human beings and cannot have the same pangs of conscience that individuals have. Furthermore, many on the working group were troubled by the notion of an institution demanding the right to opt out of the rules of society, while denying the right of individual practitioners to opt out of the rules of the institution. A full range of services must be made available by a publicly funded institution of health care and its ability to 'opt out' of PAD will be limited by the options available to patients, and by its ensuring that the individual patient will have effective access to PAD elsewhere. This is a system-wide problem of access that must be rectified by strategic planning, as, without it, allowing some institutions to opt out willy-nilly would exacerbate problems of inequity. Of course much of the need for, and exercise of, PAD will not be in acute care hospitals. But, from time to time, patients will be too ill or too fragile to be transferred. Such circumstances should require that health care institutions have a plan and policy in place to manage them.

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<sup>22</sup> <http://policyconsult.cpsso.on.ca/wp-content/uploads/2014/12/Draft-Professional-Obligations-and-Human-Rights.pdf>

#### 4.4.1. INSTITUTIONAL POLICIES FOR PAD REQUESTS

- Every health care organization must have an explicit policy for PAD, particularly for efficient handling of conscientious objection in-house. Organizations, such as hospitals, must have an identified individual (an anonymous service or service provider will not do) who will help to arrange an effective referral or find a willing provider who will come to the institution to perform PAD. They cannot simply leave it up to physicians or patients to find another willing provider.
- Whether a publicly funded institution that wishes to completely opt out of providing PAD may apply for an exemption is unresolved by the Task Force. An institution may object that PAD goes against their mission but this seems to have less force than objections from individuals.
- There is a shared responsibility among a network of institutions in society to assure Canadian residents that this service is available.
- Most palliative care doctors do not want to be the designated PAD providers or primary gateway to PAD,
- Nevertheless, every institution must provide ‘reasonable access’ to PAD. This means mandating some meaningful information on the available options and helping appropriate individuals access PAD.
- An exemption could be considered if an institution can demonstrate that they have a feasible mechanism for identifying and transferring eligible individuals who request PAD to another facility where PAD is provided. The transfer must not be overly inconvenient to the individual or family (e.g., very distant from their home, to a degree that would be a barrier to visiting or being present for the PAD). What opting out might look like must be defined and would not mean the institution’s and its doctors’ obligations to the individual would end.
- Every provincial and territorial regulatory college of the various health care professions must specify what constitutes an effective referral and a transfer of care.
- It is not acceptable grounds for a doctor to terminate a patient from his or her list because the patient has requested PAD. The circumstances of this request ought to be explored. Physicians who feel they cannot help a patient may legitimately recommend the patient find alternate care so long as (a) such alternatives exist, (b) the patient is not burdened or harmed by this transfer, and (c) the patient’s needs are looked after until a transfer of care can take place.

#### 4.5. Review and Oversight

The implementation of PAD will require that new mechanisms for review and oversight be put in place. For some Task Force members, *consultative* prospective review of some PAD decisions was thought to be a helpful, but not a required, step in decisions about PAD. This need would usually be adequately met by requiring in all cases the opinion of a second, independent consulting physician. In some cases, physicians might be able to assess the capacity of the individual to request PAD, but might still have genuine uncertainty about whether a condition would be considered irremediable. Decisions as to what constitutes an acceptable reason to grant PAD will have to be made and some professional guidance may be required. Hence the recommendation (below, section 6) of education directed at all those involved with PAD and (below in this section) of access to a consultative body that could examine complex cases and be a resource for individuals and health care providers.

The Task Force proposes there should be two mandatory levels of retrospective oversight and review and one optional level of prospective or anterograde consultation.

The first mandatory level of retrospective oversight is a provincial review committee to scrutinize individual cases to ensure compliance with regulations (individual-level oversight). There should be some data analysis at this level which should be reported in turn to the national oversight body. The second is a national data collection body that will scrutinize EOL practices as a whole, to look for the overall effects of legalizing PAD (societal oversight). Larger scale data repository and analysis will reside here. The third, an optional prospective review, is a local special consultative committee that will be available to individuals and health care providers for consultation in cases of uncertainty as regards the accessibility to, or appropriateness of, PAD services.

#### 4.5.1. PROVINCIAL REVIEW COMMITTEE

- **Function**
  - Retrospective review of all cases of PAD
  - Confidential support services should be available for health care practitioners who may experience personal hardship or trauma after participating in PAD
  - Mandatory reporting by the physician who performs PAD
    - Identification of individual, attending physician, consulting physician, and any other key inter-professional informants.
    - Diagnosis, prognosis (if known), confirmation of capacity, alternatives offered, consultations from other specialists (e.g., PC and/or psychiatry) if appropriate.
      - Duplicate forms (or e-forms) from physician and consulting physician, witnessed (one form to stay with the Provincial Review Committee; the other anonymized to go to a federal data collection and monitoring body).
    - Documentation of verbal and written requests
    - Name, dose and route of administration of medication
    - Details of death including any unexpected issues or complications
    - Whether the death appeared to have met the legal standard of hastened death (both PAD and the individual's underlying illness should be documented)
    - Whether the death was self-effected or had professional involvement
    - Demographic data such as age, gender, socio-economic status, insurance status, disabilities, functional status
    - Research on this material must be funded and carried out on a regular basis to ensure standards are met and prevent unwarranted abuse of PAD or to ensure its availability and the quality of care at the closure of life

Following the practices of other jurisdictions (Oregon and the Netherlands), physicians should be required to complete a standard form detailing the information regarding each case, much as they do currently with death certificates. Having this information in a standardized form would, especially if the document were standardized across the provinces, facilitate case-by-case review as well as data collection and analysis. Additional information that should be legislatively required from doctors would include: the reason(s) the individual made the request and the nature and

description of the individual's suffering. Express consent must be sought to ensure individual privacy when sharing information outside the individual's circle of care where not mandated by legislation. Any questions asked and data gathered must be done with a clear purpose in mind and with the strictest provisions of confidentiality.

- **Composition**

- Committee with representation of one member each from the medical and legal or ethical communities, and one public member
- Constituted at the provincial level to liaise with provincial and territorial regulatory authorities, and answering to the provincial or territorial Ministry of Health

- **Procedure**

- The committee reviews the documentation submitted by the physician to assess for compliance with regulations.
- If two-thirds of the committee find that there was a violation of the regulations, appropriate and proportionate action will be taken. For example, steps may be taken to confirm facts with the relevant parties, or appropriate referrals may be made to a regulatory college or a death investigation system.
- The committee's role is to recommend action, not to adjudicate.
  - College/prosecutor will review the case independently as they would any other referral.
- Regardless of the result, a report will be sent to the physician with the findings of the committee, along with any educational feedback deemed appropriate.

This committee should perform a data collection/analysis role as it will be the only body collecting the raw data necessary for this task. It should be required to issue an annual summary report of the cases it has reviewed to the provincial or territorial Ministry of Health and to the federal oversight body. This report must contain only anonymized data.

#### 4.5.2. NATIONAL DATA COLLECTION AND MONITORING BODY

- **Function**

- A centralized organization that collects and stewards data and vital statistics to allow monitoring and research into EOL practices as a whole.

- **Composition**

- A federal arms-length body created/funded by the federal Ministry of Health.
- Scientific experts able to perform appropriate data collection and analysis.
- A multidisciplinary body of the public, medicine, and law / ethics to interpret the findings.

- **Procedure**

- Collect copies or monitor e-reports of all death certificates / e-files and vital statistics from every death in Canada
- Requires harmonization of data collected on death certificates across provinces

- Death certificates / e-files will need to be modified to indicate care being provided at the time of death (e.g., PAD, palliative sedation, palliative care/symptom control, curative therapy)
- Survey sample of death certificates / e-files to gather more details on EOL practices:
  - Representative sampling of death certificates / e-files under the auspices of appropriate authorities;
  - Focus on cases where there may have been physician involvement in hastening death;
  - Review details about individual requests, intent of physician, degree of life-shortening, medications used, and so forth for cases that may not have been reported to the provincial oversight body or may not have been identified as PAD;
  - Review cases where PAD failed or where it may have been inappropriately denied to individuals;
  - Data accessible to any researcher subject to ethics approval and scientific review.
  - The death certificate / e-file sampling procedure would yield valuable information and has the virtue of capturing EOL practices other than PAD and unreported cases of PAD.

The Task Force recommends annual reports from this body on the operation of PAD legislation. To produce them this body will therefore also need to be collecting, analyzing, and reporting the data provided by the provincial/territorial review committees or Ministries of Health. The results should look like the annual reports by the Oregon Department of Public Health on the operation of the Death With Dignity Act.

#### 4.5.3. SPECIAL CONSULTATIVE COMMITTEE (LOCAL)

The Task Force has not yet envisioned potential areas that might require a dispute resolution mechanism, such as the Consent and Capacity Board, other than in capacity disputes. However, it does recognize that there may be circumstances where a patient or health care provider would disagree on whether a condition is ‘irremediable’ or even a ‘medical condition’ and so we propose a process in such cases involving a special consultation committee.

- **Function**

- Offer option of 2<sup>nd</sup> or 3<sup>rd</sup> opinion if there is a disagreement regarding whether the condition is irremediable.
- The special consultation committee will consider and advise only on the central question to be answered: Is this condition irremediable within the scope and meaning of the *Carter* decision?
- The special consultation committee would not address questions of capacity; this would still be the responsibility of the treating and consulting physicians and subject to potential appeal through extant processes covered by consent law

- **Structure**



- o A consultative service that would be available and comprised of one to three health care providers experienced in the area, able to render advice, and regulated by and answerable to the appropriate provincial or territorial professional and regulatory body.
- o The service would provide an opinion, but not a final decision.
- **Procedure**
  - o Individual / Physician/Health care provider could request advice concerning the appropriateness of PAD.
  - o It would provide its advice in a timely way.
  - o It would submit an annual report on its activities to the National review committee.

#### 4.6. Educational Efforts and Support

PAD will present a new element of practice for Canadian health care providers. Education will need to be aimed at those currently in practice as well as trainees. It is recognized that from the initial individual inquiry about PAD through to the individual request for and the provision of PAD, multiple health care professions will be involved and all must receive education and support appropriate to their involvement. Equally important, information and educational resources for the public and specific groups would be valuable to ensure a common baseline of understanding of terms, options, rights and safeguards. Together, an educated public and a competent provider team will support any administrative and practice framework developed to provide a safe and effective choice about PAD and alternatives.

Considering the potential individual journey from request for PAD to death, multiple interactions with health care providers can be anticipated. The recommendations for education for health care professionals are derived from this projected individual experience. It is anticipated that relevant professional schools, associations, organizations and institutions will provide education of providers. Additional learning needs and professional supports may be identified as PAD is integrated into practice and experience reveals unmet needs.

One Task Force member noted that, “there is a moral tithe to be paid for this.” Indeed, PAD is not, and will not be experienced as, the same as withholding or withdrawing treatment. Those who shoulder this responsibility will need to be supported. While physicians are ultimately the responsible professionals, other health care professionals will be involved and will also need support. Nurses, for example, do not have the same ability to withdraw their service given that this could amount to immediate abandonment, as per nursing ethics standards. And in most instances, while the physician writes the prescription, a pharmacist prepares the drug, and someone else delivers it. Practical support of those involved in the PAD process should be built into that process and also provided by their professional bodies and the institutions where they practice; moral support could be provided as part of a community team or a circle of care.

Important factors and recommendations include:

- Most inquiries about or requests for PAD will not ultimately result in PAD, therefore providers must be well versed in explaining all EOL options to individuals.



- Existing curricula on palliative care can be leveraged or expanded to improve clinician competency in discussing EOL options.
- Requests for PAD may not go directly to the physician, therefore education on referral process and counselling of individuals should be offered to interdisciplinary health care providers.
- Assessing capacity for treatment is already within the scope of practice for clinicians and teams, but it is sometimes not done well. Educational programmes for assessing capacity for decisions about PAD and EOL care will require more attention.
  - Clinicians may require additional support and education/training to increase comfort and confidence in the PAD context.
- There may be distinct and precise procedures for documentation and completion of death certificates, perhaps varying by jurisdiction.
  - Clear directives will be needed on how the death certificate will be completed, with dissemination and education to physician's/coroner's office; this could link to regulatory systems.
- Health care providers have professional and fiduciary duties under the law, as well as rights of conscientious objection to provide PAD.
  - Education and information must be available on the conscientious objection policies by all regulatory bodies to ensure that professional and fiduciary duties are maintained.
- PAD provides an opportunity to enhance education for providers and the public on EOL care options.
  - Resources developed to support the implementation of PAD ought to recognize and seek to normalize the dying process as part of the continuum of life and death.
- There will be varying levels of comfort amongst clinicians in discussing EOL care and personal values.
  - The education on and around PAD ought to also provide an opportunity to enhance clinicians' communication and values-based reflective practice skills.

## 5. Concluding Remarks

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The overall conclusion of the Task Force is that PAD in Canada ought to begin cautiously, with a well-scrutinized and strongly supported process that promotes equitable access to PAD as one of a comprehensive range of alternatives for responding to suffering and providing end-of-life care. The Task Force recognizes the complexity of the ethical, legal, and medical questions raised by PAD. Even in countries where PAD is legal and broadly accepted by the population, there are significant numbers of health care providers and members of the public who maintain a strong opposition to the practice. We must accept that there will never be any set of regulations, procedures or policies that will satisfy all, and that, whatever system is implemented in February 2016 (or shortly thereafter), it will no doubt require modifications in the future. This is the reality for any complicated ethical issue in a pluralistic society; PAD is not unique in this regard.

Ultimately, the success of implementing PAD in Canada will depend upon patients, health care professionals, administrators, politicians, and the public more generally working together in the spirit of collaboration and improving individual care. PAD has been at the centre of a long and sometimes bitter debate, but this debate must give way to a more productive process aimed at enhancing EOL care for all residents of Canada. Even our own Task Force was split at times on important issues. Our discussions revealed strongly held beliefs – beliefs which we were challenged to reconcile. Experience and evidence should continue to inform ethical EOL care and all health care practices, guided by the goal of relieving suffering. Differences of opinion and conflict represent the beginning and not the end of discussions about the exemplary and equitable EOL care that is indispensable to an ethical PAD system.

## 6. Appendices

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### 6.1. Task Force Membership

#### Chair:

- Philip Hébert, MD, PhD – Department of Family and Community Medicine, University of Toronto

#### Members:

- Erika Abner, LLB, LLM, PhD – Undergraduate Medical Education, Faculty of Medicine, University of Toronto
- Sally Bean, JD, MA – Institute of Health Policy, Management, and Evaluation, University of Toronto, and Sunnybrook Health Sciences Centre
- Monica Branigan, MD, MHSc (Bioethics) – Department of Family and Community Medicine, University of Toronto, and Mount Sinai Health System
- Kristine Arnet Connidis, SJD, Dip.An.Psych. – Law, Psychology and Psychotherapy
- James Downar, MD, MHSc (Bioethics) – Interdepartmental Division of Critical Care, Division of Palliative Care, University of Toronto and University Health Network
- Karen Faith, BSW, MEd, MSc – Independent bioethics consultant and educator
- Dianne Godkin, PhD – Trillium Health Partners
- Nadia Incardona, MD, MHSc (Bioethics) – Department of Family and Community Medicine, University of Toronto, and Toronto East General Hospital
- Malcolm MacFarlane – Community worker and caregiver
- David McKnight, MD, MHSc (Bioethics), FRCPC – Department of Anaesthesia, University of Toronto
- Kevin Reel, MSc, OT Reg (Ont) – Department of Occupational Science and Occupational Therapy, University of Toronto, and Centre for Addiction and Mental Health
- Wayne Sumner, PhD – Department of Philosophy, University of Toronto
- Frank Wagner, BA, MA, MHSc (Bioethics) – Department of Family and Community Medicine, University of Toronto

#### Students:

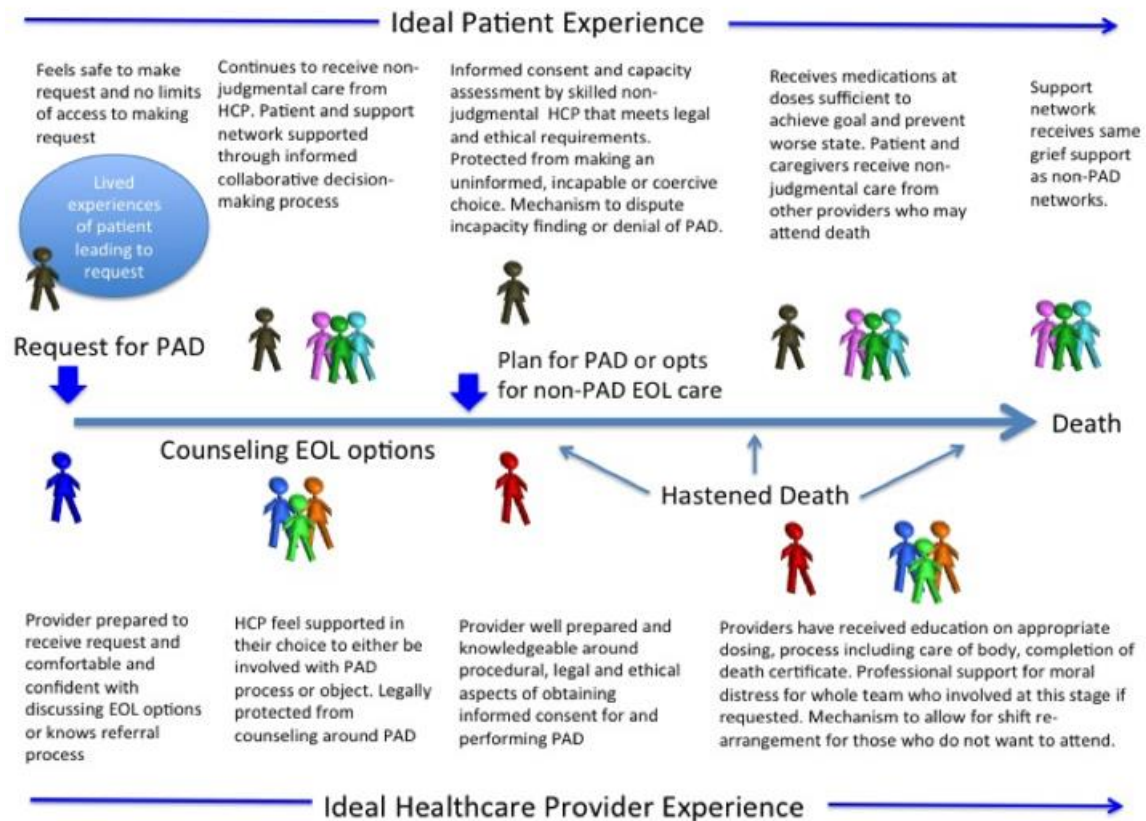
- Eva Knifed, BSc, MD – Graduate Student, MHSc Program in Bioethics, University of Toronto
- Amitpal Singh – Research Assistant and Undergraduate Student, Department of Philosophy, University of Toronto

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- Robert Butcher, PhD – Practicing healthcare ethicist (Ontario)
- Jocelyn Downie, MA, MLitt, LLB, LLM, SJD – Professor of law and medicine (Nova Scotia)
- Andrea Frolic, PhD – Practicing healthcare ethicist and assistant professor in family medicine (Ontario)
- Mark Handelman, BA, LLB, MHSc (Bioethics) – Practicing health lawyer (Ontario)

- Eric Wasylenko, MD, BSc, MHSc (Bioethics) – Palliative care physician and clinical ethicist (Alberta)
- Canadian Medical Association
- Canadian Society of Palliative Care Physicians
- College of Physicians and Surgeons of Ontario

## 6.2. Ideal Patient and Health Care Provider Experience



Credit: Nadia Incardona