

POLICY STATEMENT #4-15

# Planning for and Providing Quality End-of-Life Care

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REFERENCE MATERIALS:	See Back Page
OTHER REFERENCES:	Frequently Asked Questions
	Physician Advisory Services

### **INTRODUCTION**

Patients are entitled to receive quality end-of-life care that allows them to live as well as possible until they die. Physicians have an important role to play in planning for and providing quality end-of-life care.

Planning for end of life can ensure that the care provided to patients aligns with their wishes, values and beliefs.

Providing quality end-of-life care involves addressing and managing the physical, psychological, social, and spiritual needs of patients, while being sensitive to their personal, cultural and religious values, and beliefs. Quality end-of-life care also aims to reduce suffering, respect the wishes of patients, and lessen conflict and distress.

When engaging patients in end-of-life planning or when providing end-of-life care, it is important that physicians assist patients or their substitute decision-maker to identify meaningful and realistic goals of care that are compassionate, respectful and that seek to incorporate patient wishes, values and beliefs.

### **PRINCIPLES**

The key values of professionalism articulated in the College's Practice Guide – compassion, service, altruism and trustworthiness – form the basis for the expectations set out in this policy. Physicians embody these values and uphold the reputation of the profession by:

- 1. Respecting patient autonomy with respect to health-care goals, and treatment decisions;
- 2. Acting in the best interests of their patients;
- 3. Demonstrating professional competence, which includes meeting the standard of care and acting in accordance with all relevant and applicable legal and professional obligations;

- 4. Communicating sensitively and effectively with patients and/or their substitute decision-maker;
- 5. Collaborating effectively by recognizing and accepting the unique roles and contributions of other physicians, health-care providers, and non-health-care providers;
- 6. Participating in self-regulation of the medical profession by complying with the expectations set out in this policy.

### PURPOSE

This policy sets out the College's expectations of physicians regarding planning for and providing quality care at the end of life.

### TERMINOLOGY

Advance care planning is the process of reflection and communication where people consider what sort of treatment they may want at the end of life. It includes the deliberation and communication of wishes, values and beliefs between the individual, their loved ones, their substitute decision-maker and their health-care provider(s) about end-of-life care.<sup>1</sup>

**Cardiopulmonary resuscitation (CPR)** is a potentially lifesaving intervention that is provided with the intention of reversing or interrupting a potentially fatal event (e.g., cardiac or respiratory arrest). CPR is often understood to include chest compressions, artificial ventilation (including, intubation) and defibrillation.<sup>2</sup>

**Physician-assisted death** occurs when a physician provides<sup>3</sup> or administers<sup>4</sup> medication at the request of the patient that intentionally brings about a patient's death.<sup>5</sup>

**Potentially life-saving treatment** is treatment that is provided with the intention of reversing or interrupting a potentially fatal event (e.g., cardiopulmonary resuscitation, etc.).<sup>6</sup>

<sup>1.</sup> Adapted from Ontario Medical Association, End of Life Terminology. https://www.oma.org/Resources/Documents/EOLC\_Definitions.pdf.

<sup>2.</sup> Adapted from Canadian Medical Association, Statement on Life-Saving and -Sustaining Interventions. http://policybase.cma.ca/dbtw-wpd/Policypdf/PD14-01.pdf. 3. Often referred to as physician assisted suicide.

<sup>4.</sup> Often referred to as euthanasia.

<sup>5.</sup> Adapted from Carter v. Canada (Attorney General), 2015 SCC 5 paragraph 40. https://www.canlii.org/en/ca/scc/doc/2015/2015scc5/2015scc5.pdf.

<sup>6.</sup> Adapted from Canadian Medical Association, Statement on Life-Saving and -Sustaining Interventions.



**Life-sustaining treatment** is any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function essential to the life of the patient (e.g., mechanical ventilation, medically assisted nutrition and hydration, etc.).<sup>7</sup>

**Palliative care** is active total care that improves the quality of life of patients and their families facing life-threatening illnesses or life-limiting chronic conditions, with a focus on relieving pain and other symptoms and addressing psychological, social, and spiritual distress; it is applicable in all phases of illness, from early in the course of illness to bereavement.<sup>8</sup>

**Palliative sedation** refers to the practice of relieving intolerable suffering through the proportional and monitored use of opioids and/or sedative medications to intentionally lower a patient's level of consciousness at the end of life.<sup>9</sup>

**Substitute decision-maker** is someone who makes health-care decisions on behalf of a patient if they are incapable of health-care decision-making.<sup>10,11</sup>

### POLICY

This policy is divided into 10 sections addressing a number of issues that relate to end-of-life care:

- 1. Quality Care
- 2. Communication
- 3. Advance Care Planning
- 4. Consent to Treatment
  - 4.1 No Treatment Without Consent
  - 4.2 Capacity at the End of Life
  - 4.3 Consent on Behalf of an Incapable Patient
- 5. Interventions and Care Management
  - 5.1 Palliative Care
  - 5.2 Potentially Life-Saving and Life-Sustaining Treatment

- 5.3 Aggressive Pain Management and Palliative Sedation
- 6. Dying at Home
  - 6.1 Home Care
    - 6.2 Certification of Death
- 7. Wishes and Requests to Hasten Death
  - 7.1 Responding to Wishes and Requests to Hasten Death
    - 7.2 Physician-Assisted Death
- 8. Managing Conflicts
  - 8.1 Conflict Resolution
  - 8.2 Conflicts with Substitute Decision-Makers
  - 8.3 Conscientious Objection
- 9. Documentation
- 10. Organ and Tissue Donation

### 1. Quality Care

There are a number of medical and non-medical elements that comprise quality care at the end of life. Research and clinical experience show that what is important to patients and their families regarding quality end-of-life care may often include, but is not limited to:

- Managing pain and other distressing symptoms, including psychological issues;
- Avoiding the unnecessary prolongation of dying, especially when there is little hope for meaningful recovery;
- Strengthening relationships with loved ones and continuing active involvement in social interactions to the extent that it is possible to do so;
- Attaining feelings of peace or closure, achieving a sense of control and meaning, satisfying spiritual needs, completing important tasks, and preparing for the end of life by resolving conflicts, saying goodbye, and preparing for death;
- Having trust and confidence in a physician and having a physician who is available and takes a personal interest in the patient's care;
- Preserving dignity, being treated with respect and compas-

<sup>7.</sup> Adapted from University Health Network, Appropriate Use of Life-sustaining Treatment and Canadian Medial Association, Statement on Life-Saving and -Sustaining Interventions.

<sup>8.</sup> Adapted from World Health Organization, Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/.

<sup>9.</sup> Adapted from Ontario Medical Association, End of Life Terminology.

<sup>10.</sup> Adapted from Ontario Medical Association, End of Life Terminology.

<sup>11.</sup> For more information on substitute decision-makers please see Section 4.3 "Consent on Behalf of an Incapable Patient" of this policy or the College's Consent to Treatment policy.

sion, and being treated in a manner that affirms the whole person;

- Facilitating decision-making through clear, honest, consistent and timely communication, having the opportunity to address personal concerns, and being listened to; and
- Receiving support through the grief and bereavement process.

When planning for or providing end-of-life care, physicians must endeavour to understand what is important to their patient and/or the patient's substitute decision-maker in order to ensure that goals of care are understood and that quality care is provided. This may require providing assistance to patients or substitute decision-makers to help them articulate these goals of care. It is also important for physicians to understand and personally acknowledge that, in certain circumstances, treatment cannot prevent death.

### 2. Communication

End-of-life care situations can be highly stressful and difficult for those involved. Therefore, communication is of paramount importance. Physicians must communicate effectively<sup>12</sup> and compassionately with patients and/or substitute decisionmakers, in a manner and tone that is suitable to the decisions they may be facing. This includes, but is not limited to, initiating communication as early as possible, and as regularly and as often as is necessary to share information, helping patients and/or substitute decision-makers understand the information shared, and answering questions. Communicating effectively and frequently will build trust and confidence in the relationship between the physician and the patient or the patient's substitute decision-maker, help to relieve patient and/or substitute decision-maker anxiety and doubt, and may make future difficult conversations easier. involve family and/or others close to them in the patient's ongoing care. Involving family and/or others close to the patient in the ongoing care of a patient may be beneficial as it can, for example, help the patient understand their diagnoses, prognoses, medications, the tests that are required, and the decisions they have to make about treatment options. Such involvement can also help the family caregivers to provide more effective care at home and mitigate their own distress.

Physicians must obtain consent from the patient or substitute decision-maker to disclose personal health information about the patient<sup>13</sup> and must document this decision accordingly.

### **3. Advance Care Planning**

Advance care planning can lead to improved outcomes and quality of life, can help to ensure that the care provided aligns with the patient's wishes, values and beliefs,<sup>14</sup> and can also encourage realistic treatment goals. Physicians have a professional responsibility to engage patients in advance care planning and to understand their patients' wishes, values and beliefs regarding end-of-life care.

It is never too early for physicians to discuss advance care planning with their patients. As part of routine care in an ongoing physician-patient relationship, physicians are advised to discuss with their patients: the importance and the benefits of advance care planning and choosing a substitute decision-maker; the importance of documenting and disseminating advance care plans to their loved ones, substitute decision-maker, and their health-care provider(s); and, the importance of reviewing advance care plans throughout one's life.<sup>15</sup>

Physicians are also advised to help their patients engage in such planning by providing necessary medical information and opportunity for discussion. This could include asking patients general questions about their wishes, values and beliefs

Patients and/or substitute decision-makers may want to

<sup>12.</sup> See also the College's Consent to Treatment policy and the Consent to Treatment Frequently Asked Questions for advice and guidance regarding communication, including addressing language and/or communication issues.

<sup>13.</sup> For more information on physicians obligations regarding the disclosure of patient information see the College's Confidentiality and Personal Health Information.

See for example: Mack, J.W., Weeks, J.C., Wright, A.A., et al. (2010). End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28(7), 1203-1208. Zhang, B., Wright, A.A., Huskamp, H.A., et. al. (2009). Health care costs in the last week of life: association with end-of-life conversations. *Archives of Internal Medicine*, 169(5), 480-488.

<sup>15.</sup> Advance care planning materials and resources intended for both physicians and patients are available from a variety of organizations. For example, Speak Up (www.advancecareplanning.ca or for Ontario specific information http://www.advancecareplanning.ca/making-your-plan/how-do-i-do-advance-care-planning/provincialresources/advance-care-planning-workbook-ontario-version.aspx) and the Ontario Seniors' Secretariat (www.seniors.gov.on.ca/en/advancedcare/index.php).



regarding end-of-life care or discussing specific issues such as preferences for the location of their death, attitudes towards certain medical interventions (e.g., resuscitation, mechanical ventilation, etc.) and, as appropriate, their wishes with respect to organ and tissue donation.<sup>16</sup> Physicians are advised that they may need to initiate these discussions sensitively, over multiple occasions, as patients may not always be ready to participate.

Significant life events (e.g., death in the family or serious illness, becoming a parent, etc.) or changes in the patient's medical status (e.g., diagnosis of terminal illness, illness progression, etc.) are opportunities for physicians to confirm that advance care planning has taken place. If the patient has already engaged in advance care planning, physicians are advised to encourage patients to review existing advance care plans. If the patient has not engaged in advance care planning, physicians are advised to remind patients of the importance of this process, to create opportunities for discussion, and to encourage them to engage in the process.

Physicians are advised that advance care plans do not constitute consent; consent must always be given by the patient if the patient is capable with respect to the treatment or from the incapable patient's substitute decision-maker.<sup>17</sup> Advance care plans will help guide a substitute decision-maker in making decisions on behalf of an incapable patient.18

### 4. Consent to Treatment

The requirements for consent to treatment at the end of life are the same as the requirements for consent to treatment in other health-care situations. The following is a high level overview of physicians' obligations regarding consent to treatment. For a more detailed discussion of the legal and professional obligations for consent to treatment please see the College's Consent to Treatment policy.

### 4.1 No Treatment Without Consent

The *Health Care Consent Act, 1996 (HCCA)*<sup>19</sup> requires that physicians not provide treatment<sup>20</sup> unless consent has been obtained from the patient if the patient is capable<sup>21</sup> or the incapable patient's substitute decision-maker.<sup>22,23</sup> In certain circumstances, treatment can be provided in an emergency without consent.<sup>24</sup>

In order for consent to be valid it must be obtained from the patient if the patient is capable with respect to the treatment or from the incapable patient's substitute decision-maker, and it must be related to the treatment, informed, given voluntarily, and not obtained through misrepresentation or fraud.<sup>25</sup>

16. This could include asking about registering their consent for organ and tissue donation with the Trillium Gift of Life Network. For more information see Section 10 "Organ and Tissue Donation" of this policy.

19. Health Care Consent Act, 1996, S.O. 1996, c.2, Schedule A (hereinafter HCCA).

21. This is the case even if the patient has an advance care plan, as advance care plans do not preclude a capable patient from making a different decision at the time of care and are not directions to a health-care provider.

22. Sections 20(1) and 20(5) of the *HCCA* set out a hierarchy of persons who may give or refuse consent on behalf of an incapable patient. The substitute decision-maker is the highest ranking person on this list who also satisfies the requirements set out in Section 20(2) (see footnote 23 of this policy):

1. Guardian

3. Representative appointed by Consent and Capacity Board

- 8. Any other relative (related by blood, marriage or adoption)
- 9. Public Guardian and Trustee

<sup>17.</sup> For more information see Section 4. "Consent to Treatment" of this policy.

<sup>18.</sup> For more information on substitute decision-making, see Section 4.3 "Consent on Behalf of an Incapable Patient" of this policy.

<sup>20.</sup> Section 2(1) of the HCCA defines treatment as anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan.

<sup>2.</sup> Attorney for personal care

<sup>4.</sup> Spouse or partner

<sup>5.</sup> Child or parent or individual/agency entitled to give or refuse consent instead of a parent (this does not include a parent who has only a right of access)

<sup>6.</sup> Parent with right of access only

<sup>7.</sup> Brother or sister

<sup>23.</sup> Section 20(2) of the *HCCA* sets out additional requirements for substitute decision-makers. Specifically, the substitute decision-maker must also be (1) Capable with respect to the treatment; (2) At least 16 years old, unless he or she is the incapable person's parent; (3) Not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf; (4) Available; and (5) Willing to assume the responsibility of giving or refusing consent.

<sup>24.</sup> For more information see the College's Consent to Treatment policy.

<sup>25.</sup> Sections 10(1) and 11(1) of the HCCA.

### 4.2 Capacity at the End of Life

Physicians are entitled to presume that a patient is capable with respect to a treatment unless there are reasonable grounds to think otherwise.<sup>26</sup>

Physicians are advised to exercise caution regarding the presumption of capacity and to reassess capacity as appropriate, because in the context of end-of-life care the capacity to consent to treatment may be affected by a number of health conditions. As well, capacity is fluid, it can change over time<sup>27</sup> and depends on the nature and complexity of the specific treatment decision.<sup>28</sup>

### 4.3 Consent on Behalf of an Incapable Patient

A substitute decision-maker must give or refuse consent in accordance with the most recent<sup>29</sup> and known wish expressed by the patient, while the patient was capable and was at least 16 years of age.<sup>30</sup> If no wish is known or the wish is impossible to comply with or not applicable to the circumstances, the substitute decision-maker must make decisions in the incapable patient's best interests.<sup>31</sup>

Wishes can be general or specific in nature and can be expressed in writing,<sup>32</sup> orally or in any other manner.<sup>33</sup> Later wishes expressed while capable, whether written, oral or in any other manner, prevail over earlier wishes.<sup>34</sup> This is the case even if, for example, the earlier wishes are expressed in an advance care planning document.

The Consent and Capacity Board (CCB)<sup>35</sup> can provide assistance to either a physician or a substitute decision-maker when

a wish is not clear, when it is not clear whether the wish is applicable, or when it is not clear whether the wish was expressed while the patient was capable or at least 16 years of age. The CCB can also grant permission to depart from a wish in very limited circumstances.<sup>36</sup>

When making decisions based on the best interests of an incapable patient, substitute decision-makers must consider the following: any values and beliefs the incapable patient held while capable; any wishes the incapable patient expressed that are not binding according to the above criteria; and the impact of providing and not providing the treatment on the patient's condition or well-being,<sup>37</sup> whether the expected benefit of the treatment outweighs the risk of harm, and whether a less restrictive or less intrusive treatment would be as beneficial.<sup>38</sup>

### 5. Interventions and Care Management

### 5.1 Palliative Care

Physicians who propose or provide palliative care must clearly explain to patients what palliative care entails as it is sometimes misunderstood by patients. This includes, but is not limited to, being clear that palliative care involves providing active care focused on relieving pain and other symptoms; and addressing psychological, social and spiritual distress related to the patient's condition, which can be provided in conjunction with other treatments intended to prolong life, or when these treatments have been stopped.

Palliative care can be provided at any stage of a patient's lifethreatening illness or life-limiting chronic condition, not just in the final days or weeks of one's life. Physicians are advised

<sup>26.</sup> Sections 4(2) and 4(3) of the HCCA.

<sup>27.</sup> Section 15(2) of the HCCA.

<sup>28.</sup> Section 15(1) of the HCCA.

<sup>29.</sup> Section 5(3) of the HCCA states that later wishes expressed while capable prevail over earlier wishes.

<sup>30.</sup> Section 21(1) of the HCCA.

<sup>31.</sup> Section 21(1) of the HCCA.

<sup>32.</sup> This may include advance care planning documents, what is commonly known as an 'advance directive', in a power of attorney, or in another form. See Section 5(2) of the HCCA.

<sup>33.</sup> Section 5(1) and (2) of the HCCA.

<sup>34.</sup> Sections 5(3) of the HCCA.

<sup>35.</sup> For more information about the Consent and Capacity Board (hereinafter CCB) please visit their website: http://www.ccboard.on.ca/scripts/english/index.asp.

<sup>36.</sup> Sections 35 and 36 of the HCCA. More information can also be found on the CCB's website listed in footnote 35.

<sup>37.</sup> Section 21(2) (c) of the HCCA. This will include assessing whether the treatment is likely to: improve the incapable patient's condition or well-being; prevent their condition or well-being from deteriorating; reduce the extent to which, or rate at which, their condition or well-being is likely to deteriorate; and whether their condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

<sup>38.</sup> Section 21(2) of the HCCA.



that integrating palliative care into the treatment plan as early as possible can lead to improved quality of life for patients.<sup>39</sup> Palliative care does not have to be provided by specialists in palliative care. Physicians are, however, advised to seek the support or involvement of specialists in palliative care and/or referral to hospice care<sup>40</sup> where appropriate and available.

### 5.2 Potentially Life-Saving and Life-Sustaining Treatment

Physicians are strongly advised to discuss options with respect to potentially life-saving and life-sustaining treatments as early as possible and where appropriate. For example, when there is a change in the patient's medical status, when there are no further treatment options for a life-limiting illness or condition, or when a patient is admitted to an intensive or critical care unit. It is beneficial for these discussions to happen before events requiring a decision about potentially life-saving and life-sustaining treatment occur and for these discussions to be informed by any advance care planning done by the patient.

In accordance with physicians' legal obligations under the *HCCA*, physicians must obtain consent to provide potentially life-saving and life-sustaining treatment. However, in certain circumstances, potentially life-saving and life-sustaining treatment can be provided in an emergency without consent.<sup>41</sup>

As part of the consent process, physicians must involve the patient and/or substitute decision-maker in the assessment of the potentially life-saving or life-sustaining treatment options that fall within the standard of care. Physicians are advised that patients and substitute decision-makers may assess the value of these treatment options differently than physicians. In situations where the outcomes of a potentially life-saving and/or life-sustaining treatment are uncertain, physicians may wish to propose these treatments on a trial basis. This allows for the exploration of a possibly positive outcome while building consensus regarding the circumstances in which potentially life-saving and/or life-sustaining treatment will be withheld or withdrawn. If a trial of treatment is proposed, physicians must be clear regarding the outcomes that would warrant the continuation of treatment and the outcomes that would warrant the discontinuation of treatment.

Physicians must obtain consent in order to withdraw lifesustaining treatment.<sup>42</sup> Physicians cannot make a unilateral decision to withdraw life-sustaining treatment. As a part of the consent process, physicians must explain to the patient and/or the substitute decision-maker why they are proposing to withdraw life-sustaining treatment and provide details regarding any treatment(s) they propose to provide (e.g., palliative care). When a patient or substitute decision-maker does not provide consent to withdraw life-sustaining treatment, physicians must engage in the conflict resolution process as outlined in Section 8 of this policy which may include an application to the Consent and Capacity Board.<sup>43</sup>

There may be situations where in the physician's opinion cardiopulmonary resuscitation (CPR) should not be provided to a patient and, as such, that a no-CPR order should be written in the patient's chart. This could be for a variety of reasons, including but not limited to: that CPR will almost certainly not resuscitate the patient, that the patient's quality of life will be extremely poor should they survive, or that there are no further treatment options for the patient's underlying illness.

<sup>39.</sup> See for example: Temel, J.S., Greer, J.A., Muzikansky A., et. al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742. Zimmermann, C., Swamin, N., Krzyzanowska, M. et. al., (2014). Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*, 383(9930), 1721-1730.

<sup>40.</sup> In Canada, both palliative care and hospice care are generally used to refer to an approach to care focused on holistic care of the patient with a life-threatening or life-limiting illness and their family. However, some may use hospice care to describe care that is associated with a particular time period (e.g., final few days or weeks of life) or location (e.g., community based) (adapted from the Canadian Hospice Palliative Care Association).

<sup>41.</sup> For information on when emergency treatment can be provided without consent, please see the College's Consent to Treatment policy.

<sup>42.</sup> The Supreme Court of Canada determined in *Cuthbertson v.Rasouli*, 2013, SCC 53, [2013] 3 S.C.R. 341 (hereinafter *Rasouli*) that consent must be obtained prior to withdrawing life-sustaining treatment.

<sup>43.</sup> In *Rasouli*, the Supreme Court of Canada determined that when substitute decision-makers refuse to provide consent for the withdrawal of life-sustaining treatment that in the physician's opinion is not in the best interests of the patient, physicians must apply to the Consent and Capacity Board for a determination of whether the substitute decision-maker has met the substitute decision-making requirements of the *HCCA* and whether the refused consent is valid. See in particular paragraph 119 of *Rasouli*.

The law is currently unclear regarding the consent requirements for a no-CPR order.<sup>44</sup>

A decision regarding a no-CPR order cannot be made unilaterally by the physician. Where a physician is of the opinion that CPR should not be provided for a patient and that a no-CPR order should be written in the patient's record, the College requires physicians to discuss this with the patient and/or substitute decision-maker at the earliest and most appropriate opportunity, and to explain why CPR is not being proposed.<sup>45</sup> This discussion must occur before a no-CPR order can be written.

If the patient or substitute decision-maker disagrees and insists that CPR be provided, physicians must engage in the conflict resolution process as outlined in Section 8 of this policy which may include an application to the Consent and Capacity Board.<sup>46</sup> Physicians must allow the patient or substitute decision-maker a reasonable<sup>47</sup> amount of time to disagree before a no-CPR order can be written.

While the conflict resolution process is underway, if an event requiring CPR occurs, physicians must provide CPR. In so doing, physicians must act in good faith and use their professional judgment to determine how long to continue providing CPR.

Physicians are advised that a patient's or substitute decisionmaker's decision concerning potentially life-saving and life-sustaining treatment might change over time. As such, physicians must review these decisions with patients or substitute decision-makers whenever it is appropriate to do so, for example, when the condition of the patient changes.

### *5.3 Aggressive Pain Management and Palliative Sedation* In some cases, the management of a patient's pain and

symptoms at end of life may require the aggressive use of pain

medication (e.g., opioids) or palliative sedation (e.g., the use of pharmacological medications to reduce consciousness).<sup>48</sup> The intention of these interventions is not to hasten death. When physicians provide aggressive pain management or palliative sedation, they must provide the treatment in proportion to the pain and/or symptoms and closely follow any changes in the patient's pain and/or symptoms to ensure that appropriate treatment is provided.

### 6. Dying at Home

### 6.1 Home Care

At the end of life, patients may express a preference for staying at home as long as possible and/or for dying at home.

In these cases, physicians must help patients and caregivers assess whether home care and/or dying at home are manageable options. This includes, but is not limited to, assessing:

- Patient safety considerations;
- The caregiver's ability to cope with the situation;
- Whether the patient can be provided with the necessary care (e.g., whether round-the-clock on-call coverage is needed and available, whether home palliative care physicians or community based programs are available to assist, etc.); and
- The viability of admittance to hospice or another appropriate institution at a later date if the patient or their caregiver can no longer cope with the situation.

In addition, when considering whether dying at home is a manageable option, physicians must ensure that patients and caregivers are educated and prepared for what to expect and what to do when the patient is about to die or has just died.

If a patient decides to stay at home as long as possible or to die at home and has expressed a wish to not be resuscitated, physicians are advised to order and complete the Ministry of Health and Long-Term Care "Do Not Resuscitate Confirma-

<sup>44.</sup> The College is aware of decisions of the Consent and Capacity Board, the Health Professions Appeal and Review Board, and of various Ontario courts which relate to this question, but is of the view that the case law is not yet clear on whether consent is required prior to a physician writing a no-CPR order.

<sup>45.</sup> Physicians are advised that patients may not be aware of the limitations of CPR and the potential harms of this intervention and so are advised to clearly explain the reasons and clinical justification for not proposing CPR.

<sup>46.</sup> The Consent and Capacity Board has heard and ruled on conflicts pertaining to no-CPR or do not resuscitate orders. See for example: Sibbald, R.W. & Chidwick, P. (2010). Best interests at end of life: a review of decisions made by the Consent and Capacity Board of Ontario. *Journal of Critical Care*, 25(1) 171.el-171.e7.

What is reasonable will depend on the specific circumstances of the case (e.g., whether there are two or more substitute decision-makers, whether other family members will be consulted, etc.).
Physicians contemplating treating patients using palliative sedation are advised to consult: Dean, M.M., Cellarius, V., Henry, B., et. al. (2012). Framework for continuous palliative sedation in Canada. *Journal of Palliative Medicine*, 15(8), 870-9.



tion Form".<sup>49,50</sup> This will help to ensure that if emergency services are called that resuscitation will not be performed and that, to the extent possible, palliative care, will be provided to alleviate pain and keep the patient comfortable. Unless this form is completed and presented, emergency services are likely to use resuscitative measures and transfer the patient to hospital. When the form is completed, physicians must ensure that caregivers are instructed on the importance of keeping the form accessible and the necessity of showing the form to emergency services personnel if called, so that the patient's wishes can be respected.

Physicians must ensure that caregivers are instructed regarding whom to contact when a patient is about to die or has just died. The point of contact may vary depending on, for example, local situations or processes, health-care teams, and whether or not the "Do Not Resuscitate Confirmation Form" is completed.

#### 6.2 Certification of Death

A physician who has been in attendance during the last illness of a deceased person, or who has sufficient knowledge of the last illness, is legally required to complete and sign a medical certificate of death immediately following the death,<sup>51,52</sup> unless there is reason to notify the coroner.<sup>53</sup> Nurse practitioners who have primary responsibility for the care of the deceased are also permitted to complete the medical certificate of death in limited circumstances.<sup>54</sup> It is not acceptable to rely on the coroner to certify the death when the coroner's involvement is not required.

When a decision is made for the patient to stay at home as long as possible or to die at home, it is recommended that physicians plan in advance by designating the physician(s) or nurse practitioner(s) who will be available to attend to the deceased in order to complete and sign the medical certificate of death. It is also recommended that physicians inform caregivers of this plan.

Physicians are advised to take into consideration any local or community strategies that are in place to facilitate the certification of death.<sup>55</sup>

### 7. Wishes and Requests to Hasten Death

Patients at end of life may express a wish to hasten death, and some patients may even request their physician's assistance in hastening death. This may include requests for physicianassisted death.

49. For more information about the "Do Not Resuscitate Confirmation Form", please visit: http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ENV=WWE& NO=014-4519-45

50. These forms can be ordered by completing and submitting the Ministry of Health and Long-Term Care's "Forms Order Request". For more information please visit: http://www.forms.ssb.gov. on.ca/mbs/ssb/forms/ssb/forms.nsf/GetFileAttach/014-0350-93~2/\$File/0350-93.pdf

51. Section 35(2) of the R.R.O. 1990, Reg. 1094, General, enacted under the *Vital Statistics Act*, R.S.O. 1990, c. V.4 (hereinafter, *Vital Statistics Act*, General Regulation). The certificate must state the cause of death according to the International Statistical Classification of Diseases and Related Health Problems, as published by the World Health Organization, and be delivered to the funeral director.

52. Medical certificates of death can be obtained by contacting the Office of the Registrar General: 1-800-461-2156.

53. Section 10 of the *Coroners Act*, R.S.O. 1990, c. C.37 requires physicians to immediately notify a coroner or police officer if there is reason to believe that an individual has died: 1. as a result of violence, misadventure, negligence, misconduct or malpractice;

- 2. by unfair means;
- 3. during pregnancy or following pregnancy in circumstances that might be reasonably attributed to the pregnancy;
- 4. suddenly and unexpectedly;
- 5. from disease or sickness for which he or she was not treated by a legally qualified medical practitioner;
- 6. from any cause other than disease; or
- 7. under circumstances that may require investigation.

- (b) the death was expected during the last illness of the deceased;
- (c) there was a documented medical diagnosis of a terminal disease for the deceased made by a legally qualified medical practitioner during the last illness of the deceased;
- (d) there was a predictable pattern of decline for the deceased during the last illness of the deceased; and
- (e) there were no unexpected events or unexpected complications during the last illness of the deceased.

<sup>54.</sup> Section 35(3) of the Vital Statistics Act, General Regulation permits a registered nurse who holds an extended certificate of registration to complete and sign a medical certificate of death when:

<sup>(</sup>a) the nurse has had primary responsibility for the care of the deceased during the last illness of the deceased;

<sup>55.</sup> For example, many communities in Ontario have an expected death in the home (EDITH) protocol in place that can be accessed through the local Community Care Access Centre (CCAC) or Local Health Integration Network (LHIN). In general, it is good practice for physicians providing palliative care at home to connect with local CCAC and LHIN palliative care resources.

### 7.1 Responding to Wishes and Requests to Hasten Death

A patient's wish or request to hasten death may be a genuine expression of a desire to hasten their death, but it may also be motivated by an underlying and treatable condition such as depression, psychological suffering, unbearable pain or other unmet care needs. Patients may also be attempting to exert control over their lives, expressing acceptance of an imminent death, or seeking information about any options that may exist.

Physicians must respond to these wishes and requests in a sensitive manner. Because these expressions may be motivated by an issue that can be treated or addressed, physicians must be prepared to engage patients in a discussion to seek to understand the motivation for their expression and to resolve any underlying issues that can be treated or otherwise addressed. This may include providing more effective treatment, improving pain management strategies, providing or referring the patient for psychological counselling, seeking specialist support, and involving other professionals in the patient's care (e.g., chaplaincy support, social workers, grief counselling, etc.).

#### 7.2 Physician-Assisted Death

Physician-assisted death is prohibited by the *Criminal Code* of *Canada*<sup>56</sup> and consent of the deceased does not absolve the person who acted to bring, or assisted in bringing, about the death from criminal liability.

The Supreme Court of Canada<sup>57</sup> has determined that the prohibition on physician-assisted death is unconstitutional when a competent adult person clearly consents to the termination of life and has a grievous and irremediable<sup>58</sup> 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>59</sup>

This decision has been suspended until February 6, 2016 to

allow government, if they so choose, to develop an appropriate framework for permitting physician-assisted death. During this suspension, the existing prohibitions in the *Criminal Code* continue to apply. Once the suspension has ended the *Criminal Code* provisions prohibiting physician-assisted death will be invalid with respect to competent adults who have a grievous and irremediable medical condition and who clearly consent to the termination of life. Subject to any prohibitions or restrictions that may be imposed in future legislation or policy, physician-assisted death will be legally permitted for adults who meet these conditions.

There are jurisdictions in which physician-assisted death is permitted by law. Patients may express interest in travelling to those jurisdictions to seek those services and in doing so, may approach physicians to obtain access to their medical records or their personal health information. Patients in Ontario have a right of access to their personal health information<sup>60</sup> and unless the physician determines that an exception to this right is applicable,<sup>61</sup> physicians are required to release the medical records or personal health information to the patient in these circumstances.

### 8. Managing Conflicts

#### 8.1 Conflict Resolution

The requirements for conflict resolution at the end of life are the same as the requirements for conflict resolution in other health-care situations, although emotions may be heightened in the end-of-life care context. As such, it is important for physicians to approach conflicts with sensitivity.

In order to minimize and/or resolve conflicts that arise, physicians must:

- Communicate clearly, patiently, and in a timely manner information regarding:
- o The patient's diagnosis and/or prognosis;

<sup>56.</sup> See sections 14 and 241(b) of the Criminal Code, RSC 1985, c C-46.

<sup>57.</sup> See Carter v. Canada (Attorney General), 2015 SCC 5 (hereinafter Carter).

<sup>58.</sup> The Supreme Court of Canada also added that an irremediable medical condition will not require that the patient undertake treatments that are not acceptable to the patient (see Carter paragraph 127).

<sup>59.</sup> See Carter paragraph 127.

<sup>60.</sup> Sections 1(b) and 52 of the Personal Health Information Protection Act, 2004, S.O. 2004, c.3, Schedule A.

<sup>61.</sup> Section 52 (1) of the Personal Health Information Protection Act, 2004.



o Treatment options and assessments of those options;

- o Availability of supportive services (e.g., social work, spiritual care, etc.); and
- o Availability of palliative care resources.
- Identify misinformation and/or misunderstandings that might be causing the conflict and take reasonable steps to ensure that these are corrected and that questions are answered;
- Offer referral to another professional with expertise in the relevant area and facilitate obtaining a second opinion, as appropriate;
- Offer consultation with an ethicist or ethics committee, as appropriate and available;
- Where appropriate, seek legal advice regarding mediation, adjudication or arbitration processes that are available; and
- Take reasonable steps to transfer the care of the patient to another facility or health-care provider as a last resort and only when all appropriate and available methods of resolving conflict have been exhausted.<sup>62</sup>

### 8.2 Conflicts with Substitute Decision-Makers

If a conflict arises between a physician and substitute decisionmaker over an interpretation of a wish or an assessment of the applicability of a wish to a treatment decision, physicians are advised to apply to the Consent and Capacity Board for a determination.

If a physician is of the view that the substitute decision-maker is not acting in accordance with the substitute decision-making requirements set out in the *HCCA*,<sup>63</sup> the physician may apply to the Consent and Capacity Board for a determination as to whether this is the case and how to proceed.

### 8.3 Conscientious Objection

Physicians who limit their practice<sup>64</sup> on the basis of moral and/ or religious grounds must comply with the College's Professional Obligations and Human Rights policy.

### 9. Documentation

The requirements of medical record-keeping at the end of life are the same as the requirements in other situations.

Every patient and/or substitute decision-maker encounter and all patient-related information<sup>65</sup> must be documented and dated in the patient's record, in accordance with the College's Medical Records policy. For example, in the context of end-oflife care, patient records must include reference to discussions and decisions regarding treatment, goals of care, and advance care planning (e.g., wishes expressed while capable, advance directives, etc.). When CPR is not to be provided, this must be explicitly and clearly referenced in the patient's record so that the direction is available to all involved in the patient's care and who have access to the patient's record.

For more information about the legal requirements and professional obligations for documentation see the College's Medical Records and Consent to Treatment policies.

#### **10. Organ and Tissue Donation**

As part of quality end-of-life care, physicians can enable opportunities for their patients or substitute decision-makers to affirm an existing decision or make a decision about organ and tissue donation. *The Trillium Gift of Life Network Act*<sup>66</sup> sets out requirements relating to organ and tissue transplantation measures for health facilities designated by the Minister of Health and Long-Term Care.

A designated facility<sup>67</sup> must notify the Trillium Gift of Life Network (TGLN) when a patient in the facility has died or a physician is of the opinion that the death of a patient at the facility is imminent by reason of injury or disease.<sup>68</sup> However, the legislation provides an exception to notification if the TGLN has established exemptions for the designated facility.<sup>69</sup> Notifying TGLN in advance of any withdrawal of potentially

<sup>62.</sup> In following such a course, the physicians must comply with the College's Ending the Physician-Patient Relationship policy.

<sup>63.</sup> Section 21 of the HCCA.

<sup>64.</sup> This may include, but is not limited to, refusals to provide care, withdraw care, and/or discuss care options.

<sup>65.</sup> For more information see the College's Medical Records policy and Ontario Regulation 114/94, General, Sections 18, 19, 20 and 21, made under the *Medicine Act, 1991*, s.O. 1991, c.30. 66. *Trillium Gift of Life Network Act*, R.S.O. 1990, c. H.20 (hereinafter *TGLNA*).

<sup>67.</sup> The TGLNA defines designated facility as a hospital, health facility or other entity designated as a member of a prescribed class of facilities under section 8.2 of the TGLNA.

<sup>68.</sup> Section 8.1(1) of the TGLNA.

<sup>69.</sup> Section 8.1(2) of the TGLNA.

life-saving or life-sustaining treatment is required to ensure the patient's family is able to be approached and affirm the patient's donation decision or make a decision about organ and tissue donation on the patient's behalf.

Physicians working in designated facilities must comply with any policies and procedures established in accordance with the legislation. $^{70}$ 

Physicians who do not work in designated health facilities are advised to provide their patients with the opportunity to make choices with respect to organ and tissue donation, ideally in the context of an ongoing relationship with the patient and before any medical crisis arises. Physicians in these settings may wish to contact TGLN<sup>71</sup> for more information and/or for materials or resources, and physicians may also wish to direct patients to TGLN for more information.

### **REFERENCE MATERIALS:**

Carter v. Canada (Attorney General), 2015 SCC 5

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<sup>70.</sup> Designated facilities must establish policies and procedures for identifying and approaching potential donors and their families to provide information, and to seek consent for organ and/or tissue donation. See section 8.4 of the *TGLNA*.

<sup>71.</sup> For more information please visit the Trillium Gift of Life website (http://www.giftoflife.on.ca/). For general inquiries call toll free 1-800-263-2833 or for Referrals and Notifications call toll free 1-877-363-8456.