Advice to the Profession: End-of-Life Care

Advice to the Profession companion documents are intended to provide physicians with additional information and general advice in order to support their understanding and implementation of the expectations set out in policies. They may also identify some additional best practices regarding specific practice issues.

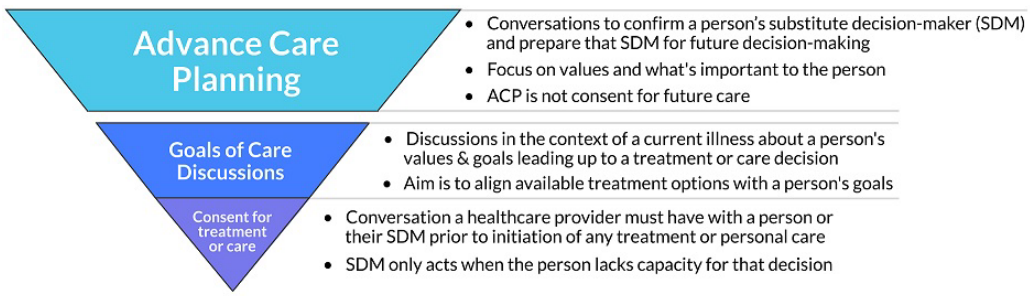
This document provides guidance on how the obligations set out in the *Decision-Making for End-of-Life Care* policy can be effectively discharged. This document also provides physicians with guidance on other specific end-of-life care issues, such as medical certificates of death and dying at home.

Advance Care Planning and Goals of Care Discussions

What are the differences between advance care planning and goals of care discussions? If I have these discussions, do I still need to obtain consent for treatment?

The main difference between advance care planning and goals of care discussions is the context of the decision-making: where advance care planning discussions take place earlier and help prepare patients and their substitute decision-makers for future decision-making, goals of care discussions occur in the context of a serious illness when there are treatment or care decisions that will soon need to be made, and help inform which treatment options may be provided.

As illustrated in the diagram below from Hospice Palliative Care Ontario's "Speak Up" campaign, neither advance care planning nor goals of care discussions constitute consent. An advance care planning discussion may outline information about the prior capable wishes of a patient and may be used to guide substitute decision-makers in providing informed consent, but it does not constitute consent to treatment. Similarly, a goals of care discussion will often lead to the development of a plan of treatment, but it does not constitute consent to treatment. Accordingly, even if you have these discussions, you will need to obtain consent from your patient or their substitute decision-maker in order to provide treatment.



What are the benefits of having timely advance care planning and goals of care discussions? What resources can I use or direct my patients to?

Having timely end-of-life care discussions can, among other things:

- lead to improved patient outcomes and quality of life;
- inform treatment decisions and ensure that the care provided aligns with the patient's wishes, as well as their personal, cultural and religious/spiritual values and beliefs;
- lessen family distress;
- increase patient comfort with physicians making decisions to write Do Not Resuscitate (DNR) orders;
- decrease hospitalizations and admissions to critical care, as well as potentially harmful or overly aggressive interventions and treatments;
- encourage realistic treatment goals; and
- help ensure the health-care team is not urgently rushing to have last-minute conversations during an emergency, for example, when a patient is experiencing a cardiac or respiratory arrest.

It is important for physicians to take an active role in helping patients and/or substitute decision-makers identify meaningful and realistic goals of care that seek to incorporate the patient's – not the substitute decision-maker's – wishes, values, and beliefs. Patients and/or substitute decision-makers may need some assistance articulating these wishes, and physicians can help them engage in this process by providing necessary medical information and opportunity for discussion.

The following websites may be helpful:

- Advance Care Planning Canada has resources and tools to assist both physicians and patients in making decisions regarding end-of-life care.
- Speak Up Ontario offers an advance care planning workbook tailored to patients receiving care in Ontario.
- Choosing Wisely Canada also has resources to help both physicians and patients get started in having end-of-life discussions.

When should I be initiating advance care planning discussions?

The policy requires physicians who provide care as part of a sustained physician-patient relationship to determine whether, based on the patient's illness or medical condition, it is appropriate to initiate an advance care planning discussion (for example, when there is a reasonable possibility that decisions will have to be made about the provision of life-sustaining treatment). That said, it is never too early for physicians to have advance care planning discussions with their patients. As part of routine care, physicians may discuss the importance and benefits of advance care planning; choosing a substitute

decision-maker; documenting and disseminating advance care plans to substitute decision-makers and health-care providers; and reviewing these plans throughout life.

When significant life events or changes in the patient's medical status occur, physicians can also remind patients of the importance of this process and encourage patients who have already engaged in advance care planning to evaluate existing care plans.

Why might it be important to involve family members and/or others close to the patient in discussions about the patient's care?

Family and/or others close to the patient can act as intermediaries; ask clarifying questions; and help patients to better understand their diagnoses, prognoses, and medications, any tests that may be required, as well as the decisions they have to make about treatment options. Involving family and/or others close to the patient in the ongoing care of a patient can also result in patients receiving more effective care and support at home and can mitigate caregiver distress.

It is important to ensure that consent is obtained to disclose personal health information about the patient whenever a patient and/or substitute decision-maker wishes to involve others in the patient's care.

Should I be documenting advance care planning and goals of care discussions?

Yes. In keeping with the College's *Medical Records Documentation* policy, physicians must document every encounter with a patient and/or substitute decision-maker and all patient-related information. In the end-of-life context, this means that physicians must document references to discussions and decisions regarding treatment, goals of care, and advance care planning, and explicitly and clearly reference when a Do Not Resuscitate (DNR) order has been placed in the patient's record.

Potentially Life-Sustaining Treatment

Can I offer potentially life-sustaining treatment to patients on a trial basis? How would that work?

Yes. There are times where the outcomes of a potentially life-sustaining treatment are uncertain, and in these instances, proposing a trial of treatment allows for the exploration of a possibly positive outcome.

When offering a trial of treatment, it is important to explain to the patient and/or substitute decision-maker which outcomes would warrant continuation and discontinuation of the treatment. It is also important to explain that when the patient and/or substitute decision-maker provide consent to the trial of treatment, they may provide consent to discontinue the treatment at a later stage if it proves ineffective.

Providing consent to discontinue the treatment up front is helpful because it eliminates the need to formally get consent from the patient and/or substitute decision-maker to stop the trial of treatment down the road.

That said, once the treatment has been initiated, patients and/or substitute decision-makers can withdraw their consent to any elements of the trial and/or withdraw their consent to discontinue the treatment at any time, and it is important to communicate this to the patient and/or substitute decision-maker. When consent to discontinue the treatment is withdrawn, the disagreement would be managed in accordance with the policy provisions on withdrawing potentially life-sustaining treatment.

What is the role of the Consent and Capacity Board? How do I find more information?

The Supreme Court of Canada[1] has affirmed that the Consent and Capacity Board (CCB) is the appropriate authority to adjudicate disagreements between physicians and substitute decision-makers regarding the withdrawal of life-sustaining treatments. The CCB is an expert tribunal, comprised of lawyers, psychiatrists, and members of the public, and is supported by full-time legal counsel. The CCB has the ability to convene hearings quickly and has the authority to direct substitute decision-makers to make decisions in accordance with a patient's prior capable wishes or best interests.

The CCB can also provide assistance when a physician believes that a substitute decision-maker is not acting in the best interests of a patient, or when clarity is required to determine a patient's wishes, whether a wish applies, or whether a wish was expressed while the patient was capable or at least 16 years of age. The CCB can also grant permission to depart from wishes in very limited circumstances.

The CCB's website (www.ccboard.on.ca) has information regarding their services. Physicians may wish to contact the CCB directly for more assistance or seek assistance from legal counsel, either from their institution, if applicable, or from the Canadian Medical Protective Association.

Withholding Resuscitative Measures

What are the legal requirements regarding withholding resuscitative measures and writing Do Not Resuscitate (DNR) orders?

In August 2019, the Ontario Superior Court released *Wawrzyniak v Livingstone*[2], which clarified that physicians are required to provide cardiopulmonary resuscitation (CPR) to a patient only when doing so is within the standard of care.

[1] In *Cuthbertson v. Rasouli*, 2013 SCC 53.
[2] *Wawrzyniak v. Livingstone*, 2019 ONSC 4900.

Where a physician determines that it is not appropriate to provide resuscitative measures, such as CPR, to a patient (i.e., that it is not within the standard of care), the physician is *not* required to obtain consent from the patient and/or substitute decision-maker prior to withholding resuscitative measures and/or writing a DNR order.

Does the College require physicians to obtain consent before writing a Do Not Resuscitate (DNR) order?

No, in keeping with the court's decision in *Wawrzyniak v Livingstone* (*Wawrzyniak*), the College does not require physicians to obtain consent from a patient and/or substitute decision-maker prior to writing a DNR order.

However, physicians have other professional expectations they must meet when writing DNR orders, and these expectations differ depending on the physician's reason for writing the order, as outlined below.

When providing resuscitative measures to a patient is medically futile

If a physician determines that providing resuscitative measures to a patient is medically futile, the physician – who has the expertise to decide whether treatment simply will not work – can write a DNR order, but the policy requires them to:

- inform the patient and/or substitute decision-maker that an order will be or has been written;
- explain to the patient and/or substitute decision-maker why resuscitative measures are not appropriate; and
- provide details regarding all other clinically appropriate care or treatment(s) they propose to provide, at the earliest opportunity.

The College does not require physicians to inform the patient and/or substitute decision-maker of the DNR order *before* it is written in this scenario, although it is good practice to do so, where possible.

When the risks of providing resuscitative measures to a patient outweigh the potential benefits

There are times where it may be possible to resuscitate a patient, but the physician determines that the risks of providing resuscitative measures outweigh the potential benefits. This risk-benefit calculation involves subjective value judgments. As a result, before making these determinations, the policy requires physicians to consider the patient's wishes, as well as the patient's personal, cultural and religious/spiritual values and beliefs, if they can be ascertained and/or the physician is aware of them. In order to respect the importance of these decisions for patients/families, the policy also requires physicians to do several things *before* writing a DNR order:

- inform the patient and/or substitute decision-maker that the order will be written;
- explain to the patient and/or substitute decision-maker why resuscitative measures are not appropriate, including the risks of providing resuscitative measures and the likely clinical outcomes if the patient is resuscitated; and
- provide details regarding all other clinically appropriate care or treatment(s) they propose to provide.

Recognizing that decisions need to be made quickly when a patient's condition deteriorates rapidly, the policy permits physicians to write a DNR order in the patient's record and *subsequently* comply with the expectations set out above where there is an imminent need to write an order. While the policy still requires physicians to consider the patient's wishes, values, and beliefs in these emergent situations, physicians do not have to discuss them with the patient and/or substitution decision-maker if there is no time to do so. However, if the physician is already aware of the patient's wishes, values, and beliefs, they are required to factor them into their decision-making.

When might a physician determine that providing resuscitative measures to a patient is "medically futile"?

Providing resuscitative measures to a patient is "medically futile" when the patient's condition is such that no intervention can successfully resuscitate the patient (i.e., provide oxygenated blood flow to the heart and brain). Some examples of when providing resuscitative measures to a patient might be medically futile include:

- A polytrauma patient has uncorrectable exsanguination where cerebral perfusion cannot be achieved by chest compressions.
- A frail patient has septic shock with progressive multiorgan failure that does not respond to optimal intensive care.
- An elderly patient has severe ischemic cardiomyopathy that is not amenable to a revascularization procedure and now presents with another myocardial infarction and congestive heart failure.

This list is not exhaustive and does not determine what is or is not medically futile. Physicians will need to use their professional judgment on a case-by-case basis to determine whether providing resuscitative measures to a patient could achieve the physiologic goals of resuscitation.

When having discussions with patients and/or substitute decision-makers about withholding resuscitative measures, it is important to keep in mind that it may be more patient-centred to explain that providing resuscitative measures would be "medically inappropriate" or "ineffective" rather than "medically futile."

When might a physician determine that the risks of providing resuscitative measures to a patient outweigh the potential benefits?

A patient's medical condition may be such that even if the patient could be resuscitated in the immediate term, it would cause more harm than good. For example:

- A patient has end-stage dementia and terminal cancer, is not verbal, and cannot eat or drink on their own. Every organ system is failing and it is clear that a cardiac arrest is imminent.
- A patient with advanced, metastatic lung cancer and a profound brain injury with no prospect of neurological recovery experiences a respiratory arrest.

Determining whether the risks of providing resuscitative measures to a patient would outweigh the potential benefits in these scenarios involves considering the patient's medical condition, as well as their wishes, values and beliefs, if they can be ascertained, and then assessing whether, among other things:

- the potential outcome would constitute a success for the patient (e.g., whether success means survival, discharge from intensive care, or discharge from hospital);
- the probability of success is sufficiently high to warrant providing resuscitative measures in light of the risks; and/or
- the patient's quality of life would be tolerable to them if they survived.

It is important that physicians consider how their own values, beliefs, and implicit biases may affect their assessment of whether the risks of providing resuscitative measures to a patient would outweigh the potential benefits. As outlined above, this risk-benefit calculation involves considering matters from the patient's point of view as much as possible.

How can I explain to a patient and/or substitute decision-maker why resuscitative measures are not being offered?

It may be helpful to explain that just as patients would not be offered a surgery or other treatment that is not within the standard of care, patients are not provided resuscitative measures that are not within the standard of care.

The policy requires physicians to inform/reassure the patient and/or substitute decision-maker regarding all other clinically appropriate care or treatment(s) they propose to provide – what does this mean?

As outlined in the policy, physicians may determine that a patient's condition is such that it is appropriate to either withdraw life-sustaining treatment or withhold resuscitative measures. However, it is critical for patients and/or substitute decision-makers to understand that even when that is the case, the patient will not be

abandoned. Rather, the patient will continue to receive all other care or treatment that is clinically appropriate, such as palliative care, surgical procedures that are clinically indicated (e.g., fracture repair), and/or chronic disease management (e.g., diuretic therapy for heart failure).

What happens if there is disagreement about the writing of a Do Not Resuscitate (DNR) order?

Given that physicians are not required to obtain consent before writing a DNR order, they can write an order even if the patient and/or substitute decision-maker disagree. However, physicians must do several things to provide support to the patient and/or substitute decision-maker at the earliest opportunity after learning of a disagreement, as set out in the policy.

In addition, there are other things physicians can do to alleviate distress if a patient and/or substitute decision-maker expresses concern about the writing of a DNR order. For example, it is good practice to review the reasons for the DNR order and consult with another physician, where appropriate.

It is important to note that disagreements between the health-care team and patient/substitute decision-maker regarding DNR orders often relate to misunderstandings about what is involved in providing resuscitative measures, and/or stem from the concern that a DNR order will result in neglect or very limited attention to otherwise treatable conditions unrelated to a cardiac or respiratory arrest. This is why it is important for physicians to review the reasons for the DNR order, as noted above.

One of the types of resuscitative measures patients and/or substitute decision-makers might request is cardiopulmonary resuscitation (CPR). It is helpful to explain that CPR generally has a very low success rate – especially for frail/elderly patients, those who have a critical illness and are in the intensive care unit, and those with serious medical illnesses, like cancer, heart disease or kidney disease – and that the risks of CPR include harmful side effects (e.g., rib fracture, pneumothorax, damage to other internal organs) and adverse clinical outcomes (e.g., brain damage, coma, memory loss, paralysis). If CPR is not successful in providing oxygenated blood flow to the heart and brain, it may mean that the patient dies in an undignified and traumatic manner.

I want to have a conversation with my patient and/or their substitute decision-maker about the patient's resuscitation code status – what should I be discussing?

Physicians can explain that full resuscitation is the default for all patients and that this means the health-care team will use any available resuscitative measure (e.g., chest compressions, artificial ventilation, etc.) to resuscitate a patient if the patient experiences a cardiac or respiratory arrest.

It can also be helpful for physicians to have comprehensive discussions with patients and/or substitute decision-makers about what, if any, interventions the patient might want to receive, and explain that because resuscitative measures include a suite of interventions, it is possible to request only some interventions and not others (e.g., some patients and/or substitute decision-makers may request compressions but not intubation). It is good practice to explain that even if a patient and/or substitute decision-maker request full resuscitation, this request may be overridden in the future if a physician determines that it would not be appropriate to provide any or all resuscitative measures to the patient. It can also be helpful for physicians to explain that if a patient and/or substitute decision-maker request Do Not Resuscitate (DNR) status, the patient will still receive all other medically appropriate care (e.g., a patient with a "do not intubate" order may still be offered a surgery that is clinically indicated and requires intubation).

Patient Death

What can I do for my patients who are receiving end-of-life care and who wish to stay at home as long as possible or die at home?

To help patients and their caregivers (including substitute decision-makers) assess whether home care and/or dying at home are manageable options, at minimum, it is important to speak to them about the following issues:

- patient safety considerations;
- the caregiver's ability to manage the situation; and
- whether the patient will be able to receive the necessary care (e.g., whether 24-hour, on-call coverage is required and available, whether home palliative care physicians or community-based programs are able to assist, etc.).

It is also helpful to speak with patients and their caregivers about what to expect and do, including who to contact, when the patient is about to die or has just died at home.

If a patient has also expressed a wish not to be resuscitated, physicians are advised to order and complete the "Ministry of Health and Long-Term Care Do Not Resuscitate Confirmation Form"[3] and inform the substitute decision-maker and any other caregivers on the importance of keeping the form accessible and showing it to paramedics if they

[3] These forms can be ordered by completing and submitting the Government of Ontario's "Forms Order Request." For more information about the "Ministry of Health and Long-Term Care 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.

are called. Unless this form is completed and presented, a paramedic is likely to use resuscitative measures and transfer the patient to hospital.

When do I have to certify a patient's death?

The *Vital Statistics Act*[4] requires physicians[5] (and in limited circumstances, nurse practitioners) who have been in attendance during, or have sufficient knowledge of the last illness of a deceased person to complete and sign a medical certificate of death immediately following the death (usually interpreted as within 24 hours following death[6]), unless there is reason to notify the coroner[7].

Completing a medical certificate of death can be logistically difficult, and so it is beneficial for physicians to designate 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 helpful for physicians to take into consideration any local or community strategies[8] that are in place to facilitate the certification of death.

How do I obtain medical certificates of death?

Physicians are able to access digital versions of the medical certificate of death online in both English and French. Physicians can also order blank hard copies of the medical certificate of death via phone (807-343-7432), fax (807-343-7694), or mail from the Office of the Registrar General, depending on their preference.

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[4] Section 35(2) of the R.R.O. 1990, Reg. 1094, General, enacted under the *Vital Statistics Act*, 1990; R.S.O. 1990, c. V.4. 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.

[5] Physicians cannot delegate the responsibility of completing and signing medical certificates of death to others (e.g., Physician Assistants).

[6] This may be extended on weekends, holidays and under unusual or special circumstances.

[7] 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: as a result of violence, misadventure, negligence, misconduct or malpractice; by unfair means; during pregnancy or following pregnancy in circumstances that might be reasonably attributed to the pregnancy; suddenly and unexpectedly; from disease or sickness for which they were not treated by a legally qualified medical practitioner; from any cause other than disease; or under circumstances that may require investigation.

[8] Many communities in Ontario have an Expected Death in The Home Protocol.