GUIDELINE

End-of-life Care

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Preamble

Principles related to end-of-life care are derived from ethical and legal principles, including court decisions and Saskatchewan legislation.

This document addresses the legal requirements and the expectations of the College for physicians dealing with end-of-life care.

Definitions

Futile care is care which cannot meet the patient's **goals of care** as defined by a shared decision making process. Futility is therefore goal specific and can be further distinguished as follows (Sokol, BMJ 2009;338:b2222).

a) **Physiological futility** is when the proposed intervention cannot physiologically achieve the goals of care. It is the most objective type of futility judgment.

b) **Quantitative futility** is when the proposed intervention is highly unlikely to achieve the goals of care.

c) **Qualitative futility** is when the proposed intervention, if successful, will probably produce such a poor outcome that it is determined that it is best not to attempt it. This poor outcome is generally a quality of life that the patient would not accept, and pursuing the intervention is therefore considered to be outside of the goals of care of the patient.

d) See **Appendix 1** for examples.

Life sustaining treatments are any therapies, medical procedures or interventions which utilize mechanical or other artificial means to sustain, restore, or supplant a vital function essential to the life of the patient (*e.g.* CPR, mechanical ventilation, medically assisted nutrition and hydration, etc.) (CPSO, Planning for and Providing Quality End-of-Life Care, Sept 2019).

Shared decision making is a process in which clinicians, members of the multi-disciplinary team, patients and, where applicable, families and substitute decision makers (SDMs) work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances potential

benefits and risks with patient preferences, goals and values. This process of shared decision making helps to define obtainable **goals of care** for the patient.

Substitute decision maker (SDM) is a person who has the legal authority to make decisions on behalf of an incapable person.

Foundational Principles

The foundational principles used by the College in developing this document include:

1) Treatment can only be provided to a patient with the consent of the patient, or, if the patient lacks capacity, according to previously expressed written wishes in an advanced care directive, or, in the absence of that, with the consent of the substitute decision-maker.
2) A physician who provides treatment contrary to the direction of a competent patient, or who provides treatment to an incompetent patient contrary to the directions set out in an advance care directive, may be found to have committed a battery on the patient.
3) Shared decision making between a physician and the patient or the patient's substitute decision-maker is the expected standard of care in addressing all care, including end-of-life care.
4) Communication with the patient and/or the patient's family or substitute healthcare decision-maker is critical. Pursuant to *The Health Information Protection Act*, a physician can only disclose personal health information to a patient's family with the consent of the patient or in circumstances in which that information can be provided without patient consent.
5) Neither the patient, nor the patient's SDM, has a right to insist or require that a physician provide or continue life sustaining treatment if, in the treating physician's opinion, that treatment is futile (See *Wawrzyniak v. Livingstone*, 2019 ONSC 4900).
6) A physician is not required to provide or continue life sustaining treatment which the physician concludes is futile.
7) Physicians who provide care to patients in end-of-life situations should inform the patient or the patient's substitute decision-maker at the earliest opportunity if the physician will not be providing or continuing certain forms of life-sustaining treatment.
8) The College recognizes that irreversible cessation of cardiorespiratory function or the irreversible cessation of all brain function constitutes death (McKitty v. Hayani, 2019 ONCA 805.)

The Guideline

Longitudinal Care and Communication

1. Communication with the patient, SDM, and/or the patient's family is critical. Communication is essential to maintaining the trust relationship between the physician and the patient, SDM, and the patient's family when addressing difficult life sustaining treatment issues.
2. When discussing life sustaining treatments that the physician believes are futile with patients and/or their SDMs, as appropriate, it is recommended that physicians consider whether to use the term **inappropriate treatment** rather than the term **futile treatment**. The term **futile**

treatment is more definitive, but the term **inappropriate treatment** may be perceived as more sensitive to the patient or the patient's SDM. (Bosslet, Am J Resp Crit Care Med 2015; 191:11).

3. It is expected that physicians who provide ongoing longitudinal care to patients whose medical condition makes it a reasonable possibility that end-of-life decisions will have to be made in the foreseeable future will:
    a. discuss those issues with the patient;
    b. encourage their patient to discuss those issues with their SDM and family;
    c. be willing to discuss those issues with the patient's SDM or family if requested by the patient; and
    d. document those discussions.
4. With respect to treatments, especially treatments at the end-of-life, shared decision making:
    a. Is the expected standard of care;
    b. Should allow the patient to exercise their autonomy in defining their goals of care based on a balance between medical expertise and their values and preferences; and
    c. Does not require a physician to provide or continue life sustaining treatments that the physician concludes is futile if the physician and the patient or the patient's SDM are unable to reach an agreement on the treatment to be provided.
5. With respect to shared decision making, patient autonomy is a negative right: a patient or a patient's SDM can refuse or withdraw treatment, but cannot demand treatment. (Downar, CMAJ 2019 November 25;191:E1289-90. doi: 10.1503/cmaj.191196).
6. Pursuant to *The Health Information Protection Act*, a physician can only disclose personal health information to a patient's family with the consent of the patient or in circumstances in which that information can be provided without patient consent. Section 27(2) of that Act allows a physician to disclose personal health information about a patient without the patient's consent subject to the following limitations:
    - The disclosure must relate to health services currently being provided to the patient.
    - The patient must not have expressed a contrary intention to a disclosure of that type.
    - The disclosure must be consistent with the ethical practices of the medical profession.

The College document *Confidentiality of Patient Information* contains additional guidance for physicians.

Consent to Treatment

7. Treatment can only be provided to a patient:
    a. with the consent of the patient,
    b. if the patient lacks capacity, according to previously expressed written wishes in an advanced care directive, or
    c. in the absence of (a) or (b), with the consent of the SDM.

8. A physician who provides treatment contrary to the direction of a competent patient, or who provides treatment to an incompetent patient contrary to the directions set out in an advance care directive, may be found to have committed a battery on the patient (Malette v. Shulman, 1990 CanLII 6868).
9. A physician may only provide treatment with the consent of the patient or the patient's SDM, or, if a SDM cannot be found, with the signed statement of another treatment provider (The Health Care Directives and Substitute Health Care Decision Makers Act). In cases of medical emergency when the patient or SDM is unable to consent, and another treatment provider is unavailable, a physician has the duty to do what is immediately necessary without consent (*Consent: A guide for Canadian Physicians* – Canadian Medical Protective Association).

Role of the Substitute Decision Maker

10. *The Health Care Directives and Substitute Health Care Decision Makers Act, 2015* establishes what constitutes capacity that allows a patient to make their own health care decisions. The legislation establishes who is entitled to act as the SDM if a patient lacks capacity.
11. Saskatchewan legislation, *The Health Care Directives and Substitute Health Care Decision Makers Act, 2015* states that SDMs are to act:
    a. according to the wishes expressed by the person requiring treatment while the person had capacity to make a health care decision, if the SDM has knowledge of the person's wishes; or
    b. according to what the nearest relative believes to be in the best interests of the person requiring treatment, if the SDM has no knowledge of the person's wishes.
12. If a physician believes that the SDM is acting contrary to the requirement(s) above, the physician should seek advice. Possible sources of advice include CMPA, the College of Physicians and Surgeons and an ethics committee. An "interested person" who believes that the SDM is acting contrary to the requirements above can apply to the Court of Queen's Bench for a court order.
13. If the directions for care of an incompetent patient set out in a health care directive are clear, those directions for care have the same effect as if given directly to the physician by a competent patient. Those directions prevail, even if the SDM, or the patient's family members disagree with those directions. *The Health Care Directives and Substitute Health Care Decision Makers Act, 2015* states:

> **5**(1) If a health care decision in a directive clearly anticipates and gives directions relating to treatment for the specific circumstances that exist, the health care decision in the directive has the same effect as a health care decision made by a person who has the capacity to make a health care decision respecting a proposed treatment.

Futility (Potentially Inappropriate Treatment)

14. A physician is not required to provide or continue life sustaining treatment which the physician concludes is futile. The refusal to provide or continue life sustaining treatment at or near the end-of-life is often made based on a conclusion that providing the treatment would be

physiologically, quantitatively or qualitatively futile (See **Definitions** and **Appendix 1**). (See Wawrzyniak v. Livingstone, 2019 ONSC 4900 and *Do physicians require consent to withhold CPR that they determine to be nonbeneficial?* – CMAJ)

15. Neither the patient, nor the patient's SDM, has a right to insist or require that a physician provide or continue life sustaining treatment if, in the treating physician's opinion, that treatment is futile.
16. Physicians who provide care to patients in end-of-life situations have an obligation, before deciding what form of life sustaining treatment will be provided, continued, withheld or withdrawn, to gather information to assist the physician to formulate their opinion as to what treatment may be futile.
17. Physicians should be aware of their implicit biases and consider whether these biases may affect their assessment of what is futile. To the extent possible, physicians should ensure that they are considering matters from the patient's point of view when determining what form of end-of-life care or life sustaining treatment will be provided. This consideration from the patient's point of view upholds the principles of shared decision making.
18. It is expected that physicians who provide care to patients in end-of-life situations will inform the patient or the patient's SDM at the earliest opportunity if the physician will not be providing or continuing life sustaining treatment or will be withholding or withdrawing life sustaining treatment.
19. The College respects and supports the medical judgment of physicians who, following the principles in the guideline, and acting in accordance with what a reasonable physician would do, decide that it is futile to provide or continue life sustaining treatment, or that life sustaining treatment will be withheld or withdrawn on the basis that treatment would be futile.
20. The College recognizes that physiological stability of patients near the end-of-life is dynamic and that physicians providing life-sustaining treatment in a critical situation may have to make difficult decisions related to providing, withholding, or withdrawing life-sustaining treatment to patients with insufficient opportunity to have the desired conversations with patients, family members or substitute decision-makers. The College recognizes that in some situations, physicians providing end-of-life care in a critical situation may not be able to communicate with family members or a substitute decision-maker before deciding whether to provide, withhold or withdraw life-sustaining treatment.
21. This Guideline does not prevent a physician from providing or continuing life sustaining treatment based upon the request of the patient or the patient's SDM, even if the physician concludes that it would be futile to provide or continue the requested life sustaining treatment.
22. The College recognizes that it can be appropriate for a physician to institute a "trial of therapy" as an interim measure to provide some level of life sustaining treatment while decisions are being made about ongoing treatment. Instituting a "trial of therapy" does not commit a physician to continuing to provide that life sustaining treatment on an ongoing basis if the physician concludes that the treatment is futile.
23. If a physician institutes a "trial of therapy", the physician should clearly communicate to the patient, the patient's SDM and/or, if appropriate, the patient's family: 1) the goal of a "trial of therapy"; 2) the length of time of the trial; and 3) how benefit or improvement will be defined.

Conflict and Conflict Resolution

24. The College recognizes that disagreements related to end-of-life care can produce distress, including moral distress, to the healthcare team and to the patient and/or their family.
25. It is essential to avoid a patient feeling abandoned if there is a disagreement related to the life-sustaining treatment between the physician and the patient, the patient's family, and/or the patient's SDM.
26. In any situation of conflict with a patient, a patient's SDM or a patient's family, physicians should be particularly careful to ensure that there is a thorough and accurate record of the interactions. That should include the physician's conclusions, plan of treatment and information provided to the patient, the patient's SDM, and the patient's family.
27. When a physician is considering withholding or withdrawing life sustaining therapy, and circumstances permit, a consultation with another physician and, if available, an ethics committee is highly recommended, especially for decisions on quantitative and qualitative determinants of futile treatment. This consultation acts as a potential safeguard against inherent bias. It also can provide some assistance to the healthcare team in dealing with the distress of disagreements related to end-of-life care.
28. If a physician decides that it would be futile to provide or continue the type of life sustaining treatment requested by a patient or a patient's SDM, or that life sustaining treatment will be withheld or withdrawn on the basis that the treatment is futile, contrary to the wishes of the patient or the patient's SDM, the physician will cooperate with the patient or the patient's SDM in transferring care to another physician or facility if requested by the patient or the patient's SDM. Such a transfer may not always be possible.
29. There should be a process developed to assist physicians who provide end-of-life care, their patients and SDMs, to address, and if possible resolve, disagreements related to the providing, continuing, withholding or withdrawing life sustaining treatment.

Appendix 1. Examples of Futility

The following are examples of futile or potentially medically inappropriate treatment, according to the **Definitions** provided above.

Physiologic Futility

- A patient is bleeding to such an extent that even with massive transfusion, the bleeding cannot be contained. The physiological stability of the patient cannot be achieved, and further aggressive life sustaining treatments may not be offered.
- A patient is on maximum physiological support in an intensive care unit and the patient has a PEA (pulseless electrical activity) cardiac arrest. The physician decides that further resuscitation cannot achieve physiological stability and no resuscitation is offered.

Quantitative Futility

- A certain chemotherapy regime will only prolong life in 5% of patients based on scientific evidence. Depending on the clinical situation and values of the patient, this chemotherapy regimen may not be offered. For example, if the goals of care of the patient are to prolong life,

then the treatment *may* be considered to be so unlikely to achieve the defined goals of care that it is quantitatively futile. The threshold of accepting or rejecting a treatment based on the likelihood of meeting the defined goals is part of the shared decision making process.

Qualitative Futility

- A patient with inoperable pancreatic cancer who insists on aggressive curative surgery (Whipple's procedure) may be refused this procedure because it may bring significant morbidity and not alter the trajectory of the expected survival.
- A patient has a catastrophic cerebral event that carries a prognosis that in 90% of patients long term institutional care is required to maintain survival. The physician is informed by the patient's SDM that the patient would never want to end up in long term care. The physician determines in consultation with specialists with expertise in outcomes and the patient's SDM that life sustaining treatment would not allow the patient to attain an acceptable quality of survival and aggressive life sustaining treatments are not offered.

Other Resources

College bylaw 7.1 – Code of Ethics for Saskatchewan Physicians

College Guideline – Confidentiality of Patient Information

Canadian Medical Protective Association: Consent: A guide for Canadian physicians