



Decision-making for the End of Life

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- COLLEGE CONTACT:** Physician Advisory Service

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PURPOSE

The purpose of this policy is to assist physicians in providing medically and ethically appropriate care to patients at the end of life; specifically, care that aims to reduce suffering, respects the wishes and needs of patients and their families, and lessens conflict and distress.

PRINCIPLES

The College believes that:

1. End-of-life care must strive to address the physical, psychological, social, and spiritual needs of patients, and where appropriate their families, with sensitivity to their personal, cultural and religious values, goals, beliefs and practices.
2. Ongoing communication with the patient or substitute decision-maker, and family if there is consent, and with other care providers is crucial to good end-of-life decision-making and care.
3. The patient or substitute decision-maker, and family if there is consent, should have the opportunity to participate in informed discussions about the care options that may optimize the quality of the patient's life while he or she is living with a life-threatening illness, and when dying. These individuals should participate in choosing the best available options, based on those informed discussions and the patient's goals, values and beliefs.

BACKGROUND: ETHICAL CARE FOR THE END OF LIFE

Definitions

For the purpose of reading this document, the following definitions of “family” and “substitute decision-maker” should be taken into consideration.

By law, when a patient is mentally capable, he or she must provide consent for the treatment decisions involved in his or her care. When the patient is not capable, a substitute decision-maker makes these decisions for the patient (see the College's Consent to Medical Treatment policy). Family members can be involved, with the consent of the patient or the substitute decision-maker, as the case may be. For practical

purposes, this document uses the phrase “patient or substitute decision-maker, and family if there is consent” to represent the authority for, and participation in, making decisions.

The word “family” as it is used throughout this document refers to those closest to the patient in knowledge, care and affection. Family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends. The patient determines who will be involved in his or her care and/or present at the bedside.¹

Further definitions can be found in Appendix 1.

Quality Care at the End of Life

Many factors influence decision-making for people who face life-threatening illnesses, including type of disease, prognosis, intensity of treatment and potential adverse effects, family issues, social factors, goals, values and beliefs, and personal priorities. Patient choices can change as the disease progresses and as the end of life approaches.

Research and experience show that patient goals for quality end-of-life care generally include the following:

Medical care:

- Management of pain and other distressing symptoms;
- Avoidance of unnecessary prolongation of dying;
- Facilitation of clear decision-making and communication.

Personal issues:

- Treatment with respect and compassion;
- Preservation of dignity;
- Affirmation of the whole person;
- Opportunity to address personal concerns;
- Achievement of a sense of preparedness, control and meaning;
- Preparation for death;
- Achievement of closure.

Relationships:

- Strengthening of relationships with loved ones;
- Relief of unnecessary burdens on others;
- Contribution to others and continued participation and active involvement in social interactions, to the extent possible.

¹ Adapted from the definition used by the Canadian Hospice Palliative Care Association.



The Role of the Physician

It is important that physicians understand and personally acknowledge that death is an acceptable outcome of care in certain circumstances, and that in many situations treatment cannot prevent death.

Physicians should aim to provide their patients with care that fulfills the goals identified previously, is compassionate and respectful, and allows patients to experience as dignified a death as possible.

Dying patients may have last wishes relating to many issues other than treatment. Physicians should endeavour to honour the last wishes of patients wherever it is possible to do so, as respect for the autonomy of the patient must continue, to the extent clinically, physically, and legally possible, to the end of life.

Physicians should ask about and seek to incorporate patient, and where appropriate, family choices, values, beliefs and goals in decisions for the end of life. In so doing, physicians should strive to understand the impact of culture and religion on the patient's personal choices.

Physicians should advocate for meaningful and/or realistic goals of care. Where appropriate for the patient or substitute decision-maker, and family if there is consent, this will involve an early discussion of diagnoses and prognosis, and of the potential benefits, burdens, and risks associated with various therapies and with the refusal of therapy.

Physicians should facilitate access to interdisciplinary pain and symptom management, palliative and supportive care, where available, even while the major focus of care is on treating the patient's disease effectively. The care should aim to help patients and, where appropriate, families cope with physical, psychological, social and spiritual needs, and to relieve unnecessary suffering.

Physicians should strive to ensure that there is communication with patients or substitute decision-makers, and families if there is consent, when treatment can no longer prevent death, and help them to reassess and revise priorities. It may be the physician or other members of the health care team who do this.

COLLEGE POLICY

PART 1: CONSENT

1.1 Capacity and Informed Consent

The requirements of informed consent at the end of life are the same as the requirements in other situations (see the Consent to Medical Treatment policy).

When the patient is mentally capable, he or she makes treatment decisions and must provide consent for the many decisions involved in his or her care, including the participation of family members. When the patient is not capable, a substitute decision-maker makes these decisions for the patient.

Informed decision-making requires that the patient or substitute decision-maker be given the information and support necessary for assessing the available options for care. In the context of decision-making for the end of life, this includes information about the potential benefits, risks and consequences of the proposed courses of action, including palliative care.

PART 2: PLANNING

2.1 Advance Care Planning

Advance care planning has been defined as the "process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions."²

As part of routine care in an ongoing physician-patient relationship, physicians are encouraged to discuss the importance of advance care planning with their patients, and to help their patients engage in such planning by providing necessary medical information and opportunity for discussion.

When patients become ill and as illness progresses, physicians should ensure that the patients' advance care instructions and wishes are reassessed with the patients or substitute decision-makers, and family if there is consent, on an ongoing basis. This may be done by the physician or by other members of the health care team.

² Teno et al, *Hastings Center Report*, 1994.

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Advance Directives

Physicians should be aware that the *Health Care Consent Act* allows a capable person to create an advance directive. Through an advance directive, a person can indicate the kinds of treatment that he or she would accept or reject should he or she become incapable. Advance care wishes need not be written and can be changed at any time. These wishes are to be interpreted by the person's substitute decision-maker; they are not directions to a health care practitioner and do not constitute a consent or refusal of consent to treatment.³

One form of written advance directive is a Power of Attorney for Personal Care ("power of attorney"). A "power of attorney" is a document which, in order to be legally valid, must meet the requirements of the *Substitute Decisions Act (SDA)*.⁴ The "power of attorney" must appoint an individual to make personal care decisions on behalf of the grantor in the event of his or her incapacity. The person appointed by the "power of attorney" is called the attorney for personal care. The "power of attorney" may or may not give the attorney special instructions about the particular kind of care that the grantor may want in specific circumstances. A physician who has any concerns about the validity of a "power of attorney" should obtain legal advice.

According to the *SDA*, health care providers may not be appointed attorneys for patients under their care, with some limited exceptions.⁵

No Advance Directives

If a person has not granted a power of attorney and becomes incapable, a substitute decision-maker will be designated in accordance with the hierarchy set out in the *Health Care Consent Act* (see the Consent to Medical Treatment policy).

Where the patient is under the age of 16, the *SDA* requires that his or her advance care instructions and wishes be considered; however, these are not binding on substitute decision-makers.

2.2 Testamentary Issues

When physicians are asked to comment on or have a concern about testamentary capacity they should make sure that they understand the legal standards for testamentary capacity and the conditions for making a valid will.⁶ Physicians who have concerns in such circumstances should obtain legal advice.

"Influencing a patient to change his or her will or other testamentary instrument in favour of a member" is an act of professional misconduct.⁷ Physicians must not pressure their patients to designate them as beneficiaries in the patient's will.

PART 3: INTERVENTIONS AND CARE MANAGEMENT

3.1 The Role of Palliative Care

Palliative care, also known as hospice care, aims to relieve the patient's suffering and improve the quality of living and dying. It may complement and enhance disease-modifying therapy or it may become the total focus of care.⁸ Palliative care can be involved at any time during a progressive life-threatening illness.

The role of palliative care practitioners and programs is to assist physicians and other team members in helping the patient and family address physical, psychological, social, spiritual and practical issues, and the associated expectations, needs, hopes and fears. Physicians should be aware that there are palliative care resources that can be consulted throughout Ontario. They should make referrals to such resources wherever appropriate and available.

Palliative care should be provided to the patient regardless of any decisions that are made concerning resuscitation or other life support measures.

3.2 CPR and Other Potentially Life-Sustaining Treatments

Physicians are not obliged to provide treatments that

³ Alzheimer Society of Ontario, Initiative #7: Advance Directives on Care Choices. Education Initiative: Advance Care Planning, January 2002.

⁴ There is no specific Power of Attorney for Personal Care (POAPC) form; rather, the requirements for creating a POAPC are that it must be a document and it must comply with the legislation. The Public Guardian and Trustee does, however, publish a booklet on Powers of Attorney, which contains forms that can be used to create a POAPC. See: www.attorneygeneral.jus.gov.on.ca/html/PGT/poa.pdf.

⁵ Section 46(3), *Substitute Decisions Act*.

⁶ More information is contained in the CMPA Information Sheet, *Physicians and their Patients' Wills: Issues to Consider*, April 2002. The CMPA website is found at: www.cmpa.org.

⁷ Ontario Regulation 856/93, as amended (made under the *Medicine Act, 1991*) s.1(1) paragraph 31.

⁸ Ferris et al (ed.), *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. Canadian Hospice Palliative Care Association. Ottawa, 2002, p 17.



will almost certainly not be of benefit to the patient.

For some patients, decisions have to be made about life support treatments. As with other decisions for the end of life, decisions regarding CPR and other potentially life-sustaining treatments should be made according to the likelihood of benefit to the patient and should take into account his or her goals, values and beliefs. The following criteria should be used to guide decision-making:

Patient is likely to benefit:

There is a reasonable likelihood that CPR and other life support will restore and/or maintain organ function. The likelihood of the person's returning to his or her pre-arrest and life-support condition is at least moderate.

Benefit to patient is unlikely or uncertain:

It is unlikely that or uncertain whether CPR and other life support will restore organ function. The subsequent prognosis is poor or uncertain and the likelihood of adverse consequences is high.

Patient almost certainly will not benefit:

There is almost certainly no chance that the person will benefit from CPR and other life support, either because the underlying illness or disease makes recovery or improvement virtually unprecedented, or because the person will be unable to experience any permanent benefit. Physicians should initiate timely discussions about treatment choices and likely outcomes with patients or substitute decision-makers, and families if there is consent, and in general, these persons should be involved in the assessment of benefit. Physicians should ensure that information about a patient's and, where appropriate, family's preferences, is elicited. This may be done by the physician or other members of the health care team.

Patients have the right to receive life-sustaining treatments that may be of benefit to them and that take into account their goals, values and beliefs. When it is not clear whether treatment might be of benefit, the choice should be made on the side of providing life-sustaining treatment. When the potential use of life-sustaining therapies is being discussed with patients or substitute decision-makers, and families if there is consent, the discussions should include the option of a trial of therapy and the circumstances under which such therapy might be withdrawn. The initiation of life-sustaining therapies does not necessarily imply that their ongoing provision

will be of benefit to the patient.

Where a physician makes a judgment about whether a treatment may be of benefit, including the initiation of life support, he or she should discuss the implications with the patient or substitute decision-maker, and family if there is consent. As with other decisions, patients who are capable with respect to decision-making have the right to refuse or withdraw consent to any treatment, including life-sustaining treatment. When the patient is not capable, the patient's substitute decision-maker can make these decisions.

When it is clear from available evidence that treatment will almost certainly not be of benefit or may be harmful to the patient, physicians should refrain from beginning or maintaining such treatment. Any recommendation not to initiate life support, or to withdraw life support, should be discussed with the patient or substitute decision-maker, and family if there is consent. If the patient or substitute decision-maker, or family if there is consent, specifically requests the physician to provide or continue the treatment notwithstanding the recommendations of the health care team, the physician should turn to the conflict resolution measures discussed in Part 4.1 of this policy in an effort to achieve consensus.

A decision not to initiate CPR or other life-sustaining treatments does not necessarily mean that any other treatment or intervention should be withheld or withdrawn. Palliative care should continue to be provided. Physicians should recognize that decisions concerning resuscitation and other life-sustaining treatments might change over time. These decisions should be reassessed whenever it is appropriate to do so; in particular, when the condition of the patient changes and when the patient or substitute decision-maker indicates that he or she has changed the decision about such treatment.

Physicians should ensure that other members of the care team are informed about treatment decisions relating to resuscitation and life support and that the discussions are carefully documented in the patient's health record.

3.3 Expected Death at Home

At the end of life, patients often express a preference for staying at home as long as possible and for dying at home. When physicians make a commitment to care for a patient at home at the end of life, they should ensure

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that the following questions are addressed:

- Is home care a manageable option? The assessment of the viability of this option should be based on the patient's wishes, the family's ability to cope, safety considerations, the availability of sufficient home care resources to meet the needs, and the availability of a health care team to provide support in the home.
- Can regular care be provided at home? If this is not possible, can the patient be referred to home palliative care physicians or to regional programs where such resources exist?
- Is it possible to ensure round-the-clock on-call coverage that will provide care in the home? Members of the health care team other than the physician may provide some of this coverage.
- Will it be possible for the patient to be admitted to an appropriate institution if the patient and his or her family can no longer cope with the situation at home?
- Is the physician prepared to undertake to certify death in the home and to arrange for another qualified person to do so when he or she is unavailable? When death of the patient at home is the expected outcome, the persons responsible for signing the medical certificate of death are to be designated in advance. It is not acceptable to rely on the coroner to certify the death.⁹

Caregivers of patients dying at home often call emergency services because they are confused about the dying process or ambivalent about foregoing life-sustaining treatment. Caregivers of dying patients need to know what to do when the patient is facing imminent death or has just died. Physicians, perhaps along with other members of the care team, should educate and prepare them for what to expect, and in particular, explain that emergency services, once called, are likely to use resuscitative measures and transfer the patient to hospital, regardless of the patient's wishes.

3.4 Euthanasia and Assisted Suicide

Euthanasia is a deliberate act undertaken by a person with the intention of ending the life of another person to relieve that person's suffering where that act is the cause of death.¹⁰ Euthanasia is prohibited under the *Canadian Criminal Code*.

Assisted suicide is the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both.¹¹ Under the *Criminal Code*, counselling, aiding or abetting suicide is an offence, and the consent of the deceased to his or her own death does not prevent criminal liability from attaching to the person who assisted in bringing about the death.

None of this is to suggest that physicians should refrain from the aggressive management of a patient's pain and symptoms, as appropriate.

PART 4: CONFLICT MANAGEMENT

4.1 Conflict Resolution

Where it becomes evident in the course of making decisions for the end of life that there is disagreement over appropriate treatment between patients or substitute decision-makers, or families if there is consent, and health care providers, physicians should ensure that appropriate conflict resolution processes are followed.

Physicians should work to bring about consensus concerning the treatment plan among the members of the health care team. Any conflicts among team members should be addressed in the absence of the patient or substitute decision-maker and the family.

To help avoid conflict, physicians should communicate in a timely manner with the patient or substitute decision-maker, and family if there is consent, concerning treatment options, any assessment of those options made by the health care team, available supportive services (e.g., social work, pastoral care) and palliative care resources. Physicians should carefully document the discussions in the patient's health record.

In the case of conflict resulting from any misinformation or misunderstanding regarding the disputed treatment, physicians should attempt to ensure that any misinformation is corrected and that any questions are answered.

If the conflict continues, where appropriate, physicians should offer the patient or substitute decision-maker, and family if there is consent, a referral to another professional with expertise in the relevant area, and should be prepared to facilitate the obtaining of a second opinion.

⁹ Physicians can sign medical certificates of death unless there is reason to notify the coroner of the death (see the *Vital Statistics Act*, the *Coroners Act* and the CPSO's Mandatory Reporting policy). Registered nurses in the extended class are now also able to sign medical certificates of death in certain situations. Registered nurses are authorized to pronounce death, and the physician may sign the death certificate subsequently. Physicians should be aware, however, that many funeral homes will not accept a body unless a death certificate accompanies it.



Physicians should also offer the patient or substitute decision-maker, and family if there is consent, access to any mediation, arbitration or adjudication processes available within the facility. This will often include consultation with an ethicist or ethics committee.

If the patient or substitute decision-maker, or family if there is consent, insists on a course of treatment that the physician feels will not be of benefit to the patient, the physician may offer to transfer care of the patient to another facility or care provider who is willing to provide that treatment. This option should be considered only after alternative methods of conflict resolution have been exhausted. In following such a course, the physician must comply with the College's policy on Ending the Physician-Patient Relationship.

The *Health Care Consent Act* provides a structure for managing conflicts about treatment decisions for incapable patients that cannot be resolved in other ways. Physicians should be aware of the relevant legislative processes.

Conflicts between health care providers and authorized substitute decision-makers arising from questions of whether the substitute decision-maker has followed the principles set out in the *Health Care Consent Act* can be addressed to the Office of the Public Guardian and Trustee (see Consent to Medical Treatment policy).

When the patient is a child who requires medical treatment, and the child's parent or the person who has charge of the child does not provide or refuses the treatment or is unavailable or unable to consent to the treatment, the physician must personally make a report to the local Children's Aid Society (see Section 1 of the College's Mandatory Reporting policy).

Conflicts about the treatment instructions contained in a Power of Attorney for Personal Care, questions of clarification about the meaning or application of such instructions, and the existence of conflicting Power of Attorneys can be addressed to the Consent and Capacity Board or the courts.

If more than one person is authorized under the *Health Care Consent Act* to consent to treatment on behalf of an incapable patient and no other individual ranks ahead of them, and they disagree about whether to give or refuse

consent, the Public Guardian and Trustee must make the decision in their stead. If a dispute arises between joint guardians or joint attorneys under a Power of Attorney in the performance of their duties, the Public Guardian and Trustee may mediate the dispute if the parties are prepared to pay the mediation fees set by the Public Guardian and Trustee, and enter into a mediation agreement as part of the process.

Physicians who have concerns about their obligations should seek legal advice.

PART 5: ORGAN AND TISSUE DONATION

5.1 Organ and Tissue Donation

The *Trillium Gift of Life Network Act* sets out requirements relating to organ and tissue transplantation measures for health facilities designated by the Minister.

Facilities prescribed in regulation under the Act must notify the Trillium Gift of Life Network of a patient's death or imminent death where a physician is of the opinion that the patient's death is imminent by reason of injury or disease.

Designated facilities must establish policies and procedures for identifying and approaching potential donors and their families to provide information, and to seek consent.

Physicians working in designated health facilities should cooperate with and contribute to any policies and procedures established in accordance with the legislation.

Physicians who do not work in designated health facilities are encouraged to provide their patients with the opportunity to make choices with respect to organ donation, ideally in the context of an ongoing relationship with the patient and before any medical crisis arises.

PART 6: DOCUMENTATION

Physicians should ensure that all interactions and discussions with patients or substitute decision-makers, and families if there is consent, as well as treatment plans and decisions, are documented in patient health records and that the records are available to the persons involved in providing medical care.

¹⁰ Special Senate Committee on Euthanasia and Assisted Suicide, 1995.

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APPENDIX: Definitions

Advance care planning:

the process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions.

Advance directive:

a form of advance care planning; a communication prepared by a mentally capable person setting out the kinds of treatment that would be accepted or rejected by that person in the event he or she becomes incapable at some time in the future. The advance directive may also designate a substitute decision-maker. An advance directive does not have to be in written form.

Assisted suicide:

the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both.

Cardiac arrest:

the cessation of the effective pumping of the heart.

Cardiopulmonary resuscitation (CPR):

measures such as chest compression, cardiac defibrillation (applying shocks to the chest over the heart), endotracheal intubation (insertion of a breathing tube down the throat), and inotrope/vasopressor administration (emergency drugs to stimulate the heart and clamp down on blood vessels). Other modalities of life support may also be attempted.

Euthanasia:

a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person's suffering where that act is the cause of death.

Family:

those closest to the patient in knowledge, care and affection. Family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends. The patient defines who will be involved in his/her care and/or present at the bedside.

Informed consent:

consent given after the patient has received information about the nature of the proposed treatment, its expected benefits, the material risks (i.e. both common and serious risks), special risks or material side effects associated with it, alternative courses of action and likely consequences of not having the treatment.

The information provided to the patient about such matters must be the information a reasonable person in the same circumstances would require in order to make a decision about the treatment. As well, the person must have received responses to his or her requests for additional information about those matters.

Life support:

refers to, but is not limited to, any of: positive airway pressure (forcing air through a facial mask manually or via a machine), endotracheal intubation, mechanical ventilation (having a machine breathe for the patient by pumping in air), temporary cardiac pacing, inotrope/vasopressor therapy, or renal replacement therapy (dialysis).

Palliative care (also hospice care, hospice palliative care):

the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Power of Attorney for Personal Care:

a legal document in which one person gives another person the authority to make personal care decisions on his or her behalf in the event he or she becomes mentally incapable.



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