Withholding or Withdrawal of Life Support: the Canadian Critical Care Society Position Paper

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SECTION 1 (PREAMBLE)

1.1 Purpose of this Document

This document is intended as both a practical guide and an educational document for members of a multidisciplinary intensive care unit (ICU) team, including physicians, nurses, respiratory therapists, the pastoral care service, social workers, and clinical ethicists, and for any individuals who are involved in "end-of-life" decision making. In providing general outlines, we hope to improve understanding of end-of-life issues. The document may be adopted or adapted for local usage in accordance with provincial legislation, where it is in place, and with individual institutional requirements.

1.2 Definitions (as applied in this document)

Life support refers primarily to the provision of any or all of ventilatory support, inotropic support for the cardiovascular system, and hemodialysis to intensive care unit patients.

Withholding/withdrawal of life support are processes by which medical therapy or intervention, including but not necessarily limited to those above, is forgone with the understanding that the patient will most probably die from the underlying disease.

Competence, in the medical consent context, refers to a person's capacity to understand the nature and consequences of his or her decision(s) to refuse or accept medical treatment. In addition he/she has the capacity to communicate the decision(s) to others. Whether or not to consider his/her refusal or acceptance informed, is contingent on his/her capacity to comprehend the material risks, as well as the perceived benefits of the proposed treatment, and any serious side effects and, thus, to appreciate

* For the Canadian Critical Care Society

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the reasonably foreseeable consequences of a decision to refuse or accept treatment.

**Substitute decision-maker.** When the patient lacks the capacity — is no longer competent — to make health care decisions, or is felt to be emotionally incapable of participating in such decision making, then an appropriate substitute decision maker should be identified and afforded the same opportunity to discuss fully the care to be provided.

### 1.3. Ethical Principles

The four basic ethical principles below are related to and complement one another. It is no criticism of them to point out that internal tensions and conflicts arise between them. These occur most frequently between respect for autonomy and the principle of beneficence, between beneficence and nonmaleficence, and between respect for autonomy and social justice. The conflicts and tensions between the principles create ethical dilemmas which we all face in our ICUs. Broader familiarity with the elements of this document will, we hope, assist in the resolution of the dilemmas and conflicts we face.

**Beneficence** requires that our actions be of benefit to patients by relieving pain and suffering, promoting health, and treating illness.

**Nonmaleficence,** the principle of "do no harm", requires that unavoidable suffering or harm be justified by a reasonable expectation of a beneficial outcome. This requires us to refrain from actions where the net outcome is harm.

**Respect for autonomy** asserts the right of competent patients to accept or refuse offered medical care. This would include the right to accept or refuse life support. Patients/substitute decision makers have a right to be provided with all information necessary to make an informed decision. This requires a careful explanation of the nature and implications of proposed interventions, which provides an understanding of the consequences of any decisions to accept or forgo life support. Competent patients may preserve their autonomy in future states of incapacity by writing down, in advance, their treatment preferences, or by designating a substitute decision maker to represent them when they are no longer competent (see Section 2.6).

In clinical situations there are at least two autonomous agents, for example, the patient/substitute decision maker and the physician(s), each with her/his own responsibilities, values, and belief systems, which necessitates respect for the autonomy of each other. In this setting, when the reasonable physician, acting in good faith, makes a medical judgement that specific intervention(s) are without medical benefit and/or fall outside accepted codes of practice, and that there is no net benefit over harm, our respect for patient autonomy does not oblige the physician to acquiesce to the request of the patient/substitute decision maker for that intervention (see also the CMA policy statement. CMAJ 1999; 160(12): 1757–1760).

**Social justice** commits us to the principle that all patients should have equitable access to life-supportive care, unless that care has no rational expectation of an outcome acceptable to the patient/substitute decision maker. We should be committed to an unbiased allocation of medical resources in a way which maximizes chances of successful intensive care treatment, and which is consistent with established standards of medical practice and the available resources of each hospital. We recognize that appropriate requests for an ICU admission may exceed an institution's ability to provide for such a request. In this situation, how does the ICU physician and his/her team choose, decide, and justify the choices made? Beyond the principles discussed immediately below in 2.1(i), a full discussion of this question in terms of the differing and sometimes conflicting theories of justice falls beyond the scope of this paper. This question ultimately has to be examined in the context of both governmental health care policy and decisions, and the needs of individual institutions.

### SECTION 2

#### 2.1 ICU Admission: Recommended Approaches to Decision Making

(i) Using their best clinical judgement, members of the ICU team should determine whether or not provision of life support, in seemingly hopeless circumstances, would merely artificially prevent the natural death of the patient. The ICU attending physician may then reasonably decline a request for admission to the ICU. Whilst patients may choose to refuse admission to an ICU, even when doing so puts them at risk of death or disability, the ICU team should be under no obligation to acquiesce to requests from patients/substitute decision makers or medical colleagues to provide life support, if this care will not be effective and is not in accord with standard medical practice or norms.

(ii) If there is reasonable doubt or uncertainty about whether the patient's medical condition
is irreversible, intensive care should be initiated, but regularly reviewed for appropriateness. If recovery is highly unlikely, life support should generally be neither initiated nor continued.

(iii) An ICU admission should not be detrimental to current ICU patients by virtue of an unreasonably hastened discharge.

(iv) Patients in the ICU would usually be candidates for CPR. However, a decision to forgo CPR should not, in and of itself, exclude patients from the ICU for other treatments, if real and substantive benefits are probable.

(v) Compassionate recognition of particular individual’s or family’s needs may, on occasion, justify a trial of treatment as a temporary measure to assess whether clearly delineated goals can be met, with the understanding that, if these goals are not met, the treatment will be discontinued.

2.2 Withholding/Withdrawal of Life Support — Is There a Difference?

(i) From a traditional ethical point of view there is no difference between the two. If life support can be withheld, it can also be withdrawn.

(ii) Withholding versus withdrawal of life support can be, and often is, a source of difficulty. Consider the following situations:

The ICU team considers it appropriate to withdraw life support. The patient’s family or loved one(s) may feel the health care professionals, and the above all the physician, have failed in their commitment to the patient.

Alternatively, the ICU team considers it inappropriate to provide life support. The family or loved one(s) may well feel the ICU team, and the physician in particular, lack the commitment to the patient which the special relationship between patient and physician implies.

These two situations illustrate familiar professional conflicts which generate apprehension and perplexity among ICU staff, patients, families, and loved ones. In addition, there are other implications connected with issues of withholding versus withdrawal of life support. These include psychological, sociological, religious, and moral concerns (see Section 4.1, Appendix 1).

(iii) Nonetheless, it is generally better to provide treatment, with a strategy in place for later withdrawal if it is either of no medical benefit or proves too burdensome, than to withhold treatment altogether because of unfounded fears about treatment withdrawal.

(iv) When it is not clear if treatment will be effective, the choice should be made on the side of life, and treatment should be provided, if this treatment is in accord with the patient’s goals. On the other hand, when it is clear treatment will not be effective and is not in accord with standard medical practice or norms, the physician is not obliged to begin, continue, or maintain the treatment.

2.3 Withdrawal of Life Support: the Decision Making Process

(i) Clarification of and consistency in the goals and objectives for the provision of life support will help patients, families, and the ICU team to reach consensus within the context of the decision making process. If the ICU team feels that continued provision of intensive care is equivalent to prolongation of the dying process, the ICU attending physician should seek to establish consensus with medical colleagues that continued life support is inappropriate. These consultations should take place prior to initiating discussions with the patient or family concerning limitation of treatment. Similarly, requests from patients/families in regard to withholding/withdrawing life support should be discussed with and between members of the health care team to ensure full understanding of the issues and to ensure that everyone is clear on process prior to implementation.

(ii) The patient/substitute decision maker and/or family are, as noted above, participants in the decision making process. Each of these participants has to deal privately with emotions which may be inescapably painful, in a milieu which can be experienced as dehumanizing, while trying to deal with a sense of personal purposelessness. In the decision making process, the patient/substitute decision maker and/or family needs to see the human face of medicine — sensitivity, attention, understanding, and patience. Good communication between the ICU team, patient/substitute decision maker, and family can enhance mutual trust and diminish the possibility of conflict between staff, patients/substitute decision makers, and families. The ICU team should always use language lay persons can understand.
(iii) If there is reasonable doubt or uncertainty about whether the patient's medical condition is irreversible, intensive care should be continued, but regularly reviewed for appropriateness. If recovery is highly unlikely, life support generally should not be prolonged and/or should be discontinued.

(iv) Consultation between the several members of the ICU team is essential in order to achieve and maintain consistency in their communication of information to the patient and/or substitute decision maker. Similarly, there is a need for consistency between the ICU team and involved consulting services.

(v) It is important to recognize the influences of nonmedical factors in discussions concerning withholding/withdrawal of life support. These include:

(a) each patient's hopes and fears, attitudes to life and death, awareness of her/his own vulnerability and mortality, and the vulnerability of those she/he loves. Patients may have deeply held religious beliefs which have shaped their attitudes to life and death, and which have, by extension, influenced their beliefs and feelings about withholding or withdrawal of life support. If the patient lacks the capacity to participate in discussion(s) of withholding or withdrawal of life support, then the substitute decision maker is the resource person with whom these issues should be discussed.

(b) the moral, ethical, religious, and social values held by members of the ICU team, and the ICU team's perception of any or all of these values held by their patients. Individual views of the ICU team members must not interfere with the provision of unbiased and nonjudgemental care. Multiple faiths are actively practiced in Canada, and healthcare professionals frequently deal with patients whose faiths are different from their own. In such circumstances the institutional pastoral care service may be a helpful and useful resource (see also Section 4, Appendix 1).

(vi) Since families, substitute decision makers, and members of health care teams may need time to come to terms with the impending death of a patient/loved one, any recommendation to withdraw or limit ICU care should be discussed with compassion by the ICU team. It may seek the advice of the ethics consultation service and/or a clinical ethicist if available, the pastoral care service, and/or other available institutional resources. In addition the following considerations apply:

- Beneficence and compassion require that the process be unhurried.
- A calm, honest description of the reasons to consider limitation of care should be given in terms that avoid medical jargon and that are easily understood by family members.
- Family members will be given the opportunity to participate fully in discussions regarding the withholding or withdrawal of life support, if the competent patient wants them involved.
- It is to be expected that initial discussions may not be understood, despite the best intentions of the ICU team, and further meetings with involved parties may be necessary.
- Despite our best efforts, patients and families may have a sense of abandonment. Every effort should be made to minimize this.

(vii) During discussions, the bedside nurse should be present. It may be appropriate, if the patient, family, and/or significant others request this, to seek the additional presence of an appropriate pastoral care provider. The discussion or discussion content and discussants should be recorded in the medical and nursing charts.

(viii) It is appropriate, when involving a patient in discussions about his/her medical condition and treatment, to consider the degree of physical or emotional burden to be imposed on the patient by these discussions. The burden may be judged sufficient for information to be withheld for a time, until it can be lightened. It is important to distinguish between the patient who has expressed the wish not to know his/her medical condition and the patient who has not expressed this wish. A physician who overrides the former's wish is not respecting the patient's autonomy. To the contrary, it is a violation of it and is an expression of inappropriate paternalism.

In contrast, the physician who considers the readiness of the patient to accept full disclosure of his/her condition acts beneficently by waiting until his/her distress is lessened. In so doing, the basic element of trust can remain intact, thus making it easier
for both to continue subsequent discussions where full disclosure can take place.

(ix) Where disagreement arises among members of the health care team and/or the family, intensive care measures should continue until further discussions have resulted in consensus on how best to proceed in the interests of the patient (see Section 3).

2.4 A Respectful and Dignified Death

(i) Once decisions are made to forgo life support, the goals of patient care in the ICU focus on comfort care, relief of suffering, and a pain-free death. Despite conscientious efforts of the ICU team to achieve these goals, they may not always be attainable. However, we ought to endeavour to provide a respectful, caring, and peaceful environment in which the patient may have a dignified death, and, in the dying process, ensure the patient is not abandoned.

(ii) Beneficence and compassion require the health care team to support and aid the preparations of the patient and relatives/friends for the impending death of the patient. This may include, if necessary, prolonging life sustaining efforts until completion of all reasonable social and spiritual obligations.

(iii) In withholding or withdrawal of life support, the ICU team may use opiates and/or other sedatives recognized to relieve suffering. In achieving this goal, the medication(s) may accelerate or hasten the forthcoming death from the underlying disease. The Report of the Special Senate Committee on Euthanasia and Assisted Suicide (1995) recognizes "that treatment aimed at alleviating suffering that may shorten life is legal." Under current Canadian law, euthanasia is not permissible. The same report defines euthanasia as "a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person's suffering, where the act is the cause of death."

2.5. Withholding and Withdrawing Life Support at the Request of a Competent Patient — Considerations

(i) A patient, formally assessed and deemed competent, has the right to forgo or request withdrawal of all forms of medical therapy, including life support. Despite the fact that it is not easy for the following criteria to be met in an ICU, nonetheless the patient's decision is to be made voluntarily, free of any coercive influence, force, or fear. The decision should be made preferably when the patient is stable, not when competency is or is potentially compromised by use of medication or by a life-threatening situation. Complying with a patient's wishes to forgo offered intervention is distinct from euthanasia or physician-assisted suicide.

(ii) This request may cause discomfort among some members of the ICU team, who may feel a conflict between the patient's request and their own value systems. An institution must not require health care workers to violate their own beliefs. In such instances, the institution must be supportive of its workers, and provide, if necessary, alternative work opportunities during times of personal crisis and a return to the usual workplace without prejudice to career development.

(iii) When a family expresses opposing wishes or views to those expressed by a competent patient, these views should be recorded and discussed, but they must not be allowed to override the choices expressed by the patient.

(iv) When life support is withdrawn, distress for both the patient and the patient's family must be minimized. The principles in Section 2.4, above, apply.

2.6 Advance Medical Directives (see also Section 4, Appendix 2)

(i) An advance directive is defined by the Senate Committee Report of 1995 as a document executed by a competent individual concerning health care decisions to be made in the event that the individual becomes incompetent to make such decisions. The purpose of the advance directive is to maintain the autonomy of the writer beyond the loss of competency. It is directed to the family, significant other(s), his/her physician, and lawyer. A copy of the advance medical directive should accompany the patient when he/she is admitted to a health care facility.

Advance directives can be divided into two categories: instruction directives and proxy directives, also known as durable powers of attorney for health care. In an instruction directive, an individual sets out what or how health care decisions are to be made in the event that she or he becomes incompetent. In a proxy directive, an indi-
vidual sets out who is to make health care decisions in the event that he or she becomes incompetent. The instruction directive and proxy directive may be combined (see CMA policy summary. CMAJ 1992; 146(6): 1072A).

An advance directive does not depend on the existence of legislation to be valid. In addition, many different types of advance directive are being promoted and/or are in use across Canada, for example, generic, disease specific, and institutional. Requirements of provincial legislation should be followed by the physician and it is her/his duty to know what these requirements are. The institution’s legal counsel could be a helpful resource for information on this subject.

(ii) When there is no advance medical directive, but when a previously competent and informed patient’s wishes and preferences are known and were clearly articulated at a time when the patient was competent — for example, not wanting cardiopulmonary resuscitation (CPR) under any circumstances — then there is an obligation to act in accordance with these wishes.

2.7 Dealing with Situations in which Patients Lack Decision Making Capacity and there is No Advance Medical Directive

(i) When possible, a substitute decision maker should be identified and should participate in the decision making process on the patient’s behalf.

(ii) The identified substitute decision maker is the recognized source of consent or refusal to forgo or undergo therapy and/or other measures. The fundamental purpose or role of the substitute decision maker is to state or express the choices the patient would make if he/she had the capacity to do so.

(iii) When no substitute decision maker is available, each health care facility has a responsibility to provide an appropriate individual to act in this capacity, in accordance with requirements of provincial legislation. As a last resort, the courts can appoint a guardian for the incompetent individual.

(iv) Statements made by incompetent patients do not supersede decisions made by the patient’s substitute decision-maker, or the patients’ own statements when they were competent. Examples might include situations such as the following:

(a) if a patient expressed her/his wishes regarding CPR after she/he lost competency, then the physician would be subject to the patient’s substitute decision-maker concerning this issue. Conversely,

(b) in a situation where intubation is deemed appropriate and the patient, while competent, stated a wish to be intubated, but overturned his/her own statement after he/she became incompetent, the physician should intubate, even if this in disagreement with the wishes of the substitute decision-maker. This reflects respect for the expressed wishes for appropriate treatment made by the patient when competent.

(v) In circumstances beyond (iv) (b), above, where the patient remains incompetent, we are obliged to seek guidance from her/his substitute decision maker.

2.8 Decision Making for Incompetent Patients

(i) The process of decision making for incapacitated or incompetent patients should be guided by one or more of the following three standards:

(a) Substituted judgement. This requires a substitute decision maker to endeavour to reach the decision an incapacitated patient would make if he/she had the capacity to make the choice. In this undertaking, the patient’s own conception of well being is respected, as is his/her interest in self-determination. The substituted judgement standard or principle promotes the underlying values of self-determination better than the “best interests” standard does.

(b) Best interests. On this standard, The President’s Commission Report on Deciding to Forgo Life-Sustaining Treatment (1983) comments “… When a patient’s likely decision is unknown, however, a decision maker should use the best interests standard and choose a course that will promote the patient’s well being as it would probably be conceived by a reasonable person in the patient’s circumstances.” In addition, this standard should assess the burdens and benefits of any proposed course of action.

(c) Pares patriae. Justice La Forest characterized pares patriae in the following way:

“The pares patriae jurisdiction is … founded on necessity, namely the need to act for the protection of those who
cannot care for themselves. The courts have frequently stated that it is to be exercised in the “best interest” of the protected person, or again, for his or her “benefit” or “welfare”. — Re Eve, [1986] 2 SCR 388.

SECTION 3

3.1 Consensus Building

If conflicts arise and/or a course of action proposed by the patient, substitute decision maker/family, or ICU team violates ethical, religious, professional, or personal convictions of any of these parties, the physician should initially explain his/her position to the patient and/or substitute decision maker, and family members. If consensus cannot be built at this level in a timely fashion, then resolution should be sought through any or all of (i) to (iv), below, and/or in accordance with the CMA policy statement (CMAJ 1999; 160(12): 1758-1760).

(i) Second, and possibly third, independent opinions from other physicians with intensive care expertise may help all parties reach a better understanding of the issues and thus facilitate arrival at consensus.

(ii) Further attempts at conciliation. These might include extended discussion with patient, family, other health care workers, and clergy.

(iii) Meeting of all parties with an impartial third party such as an institutional ethics committee or equivalent.

(iv) There should be consideration of transfer of care of the patient to an alternative physician or institution (though this may not be practicable).

(v) If an impasse remains between family and the ICU team, there should be recourse to either mediation or adjudication.

3.2 Review of Decisions

(i) If a competent patient changes his/her mind regarding their expressed wishes, the latest expressed wishes prevail in the context of offered treatment, whether or not they confirm or contradict earlier decisions.

(ii) Decisions in regard to life support are to be reviewed if there is a significant and unexpected change in the person’s condition which might alter the previously stated prognosis on which basis the previous decision was made.

SECTION 4

1.1. Appendix 1 — Religious, Theological and Philosophical Issues

The population served by each hospital or health care facility is a microcosm of Canada’s culture, ethnic background, and heritage. Due to the diversity both within and between the various religious faiths practiced in Canada, ICU team members may find themselves in circumstances where the religious beliefs held by their patients/families are in conflict with their own, and/or with proposed changes to life support measures. The ICU team should be sensitive to the differing approaches to allowance (or not) of withholding or withdrawal of life support as held by each individual faith. Thus, there is a need to be conversant with the religious beliefs of patients and families when there is any consideration of withholding/withdrawal of life support. In these circumstances early involvement of the relevant pastoral care service is recommended.

Those seeking further understanding of the relationship between religion, theology, and philosophy, and the role of the four ethical principles in clinical practice — which constitute the fundamental ethical framework of this document — are recommended to consult Principles of Health Care Ethics, Raanan Gillon and Ann Lloyd, editors. Chichester: John Wiley & Sons, 1994. The following papers therein are highly recommended both for their comprehensiveness and elucidation of topics under discussion:

(i) Preston RH. The four principles and their use: the possibilities of agreement between different faiths and philosophies.

(ii) Finnis J, Fisher A. Theology and the four principles: a Roman Catholic view I.

(iii) Hoose B. Theology and the four principles: a Roman Catholic View II.

(iv) Habgood J. An Anglican view of the four principles.

(v) Steinberg A. A Jewish perspective of the four principles.

(vi) Serour GL. Islam and the four principles.

(vii) Hasan KZ. Islam and the four principles: a Pakistani view.

(viii) Florida RE. Buddhism and the four principles.

(ix) Stopes-Roe H. Principles and life stances: a humanist view.

Some further examples of differing religious/ethnic approaches to health care can be found in the Section 4.3.

4.2 Appendix 2: Legal Considerations

Legislation varies from province to province in regard to the scope of advance directives (in-
struction and/or proxy), and procedures to be followed regarding witnesses, substitute decision making, and activation of the advance directive. Intensive care teams need to be aware of local legislation and to follow it.

**Alberta**

**British Columbia**
- BC is enacting a new adult guardianship legislation to be made up of four separate Acts.
  - Representation Agreement Act, R.S.B.C. 1996, c. 405
  - Health Care (Consent and Care Facility (Admission) Act, R.S.B.C. 1996, c. 48.

**Manitoba**

**Newfoundland**

**Nova Scotia**
- Medical Consent Act, R.S.N.S 1989, c. 279.

**Ontario**
- Substitute Decisions Act, S.O. 1992, c. 30

A recent judgement by JA Robins during the Ontario Court of Appeal Decision in Fleming v. Reid (1991), 4 O.R. (3d) 74 at 85-86 (Ont. C.A.) is quoted below:

"A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forego treatment, in the absence of some overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others."

"To deprive involuntary patients of any right to make competent decisions with respect to such treatment when they become incompetent, and force them to submit to such medication against their competent wishes and without the consent of their legally appointed substitute decision makers, clearly infringes their Charter right to the security of the person."

**Prince Edward Island**
- Consent to Treatment and Health Care Directives Act. S.P.E.I. 1996, c. 10. (not in force yet)

**Quebec**
- Arts. 10-25 Quebec Civil Code

**Saskatchewan**
- The Health Care Directives and Substitute Health Care Decision Makers Act, S.S. 1997 c. H-0.001.

**The Yukon**

**New Brunswick, Northwest Territories, and Nunavut**
No legislation as yet.

Full copies of the legislation for each province can be obtained from the Offices of the Canadian Critical Care Society.

4.3. SUGGESTED READINGS

**Position Statements/Policies:**

Spiritual/ethnicity Issues:

Some Related Articles (1994 – current, by year of publication):
6. Luce JM. Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. Crit Care Med 1995; 23: 760-766.


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