

A stylized white ECG line graphic is overlaid on a dark blue background with a light blue grid. The line starts with a small peak, followed by a sharp, tall peak, then a series of smaller, regular peaks and troughs.

CRITICAL CARE ACCESS AND CONSENT

Toolkit for Health Practitioners

Critical Care Services Ontario | March 2014
Version 1.0

This document is a product of Critical Care Services Ontario (CCSO)

Critical Care Access and Consent Toolkit is the result of a collaborative effort between CCSO, led by Dr. Bernard Lawless [Provincial Lead, Critical Care and Trauma] and a group of Subject Matter Experts (SMEs). Supported by CCSO, the team of SMEs proficient in the area of critical care and ethics informed the development of this document and the inclusion of tools that are considered best practice in addressing the issues of consent and decision-making. Content and tools included in this document are evidence based where possible and a result of careful thought, numerous discussions, direction and feedback through a transparent process.

The purpose of this toolkit is to clarify the legal and ethical obligations embedded in the consent process as outlined in the Health Care Consent Act (HCCA). Thus it is designed to complement (not replace) existing practices and resources that hospitals may have in place that meet the HCCA requirements. The tools included in this document can be applied broadly to other groups of patients as well as critically ill patients in the ICU.

How to Use This Document

The Toolkit serves two functions. The first is to provide information. The document guides users through some of the ethical issues that arise in critical care and describes step-by-step the processes related to obtaining informed consent.

The second function is to provide users with the tools that can be used during a patient's stay in the critical care unit and support facilitation of the consent process, e.g. discussing treatment options or having end of life discussions. The toolkit can be used by ICU teams to guide day to day decision making, and it can be used as a useful training resource.

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Disclaimer: *The purpose of this toolkit is to act as a resource for health practitioners. In making decisions, health practitioners must use their judgment for individual patient encounters. Every effort was made to include tools and practices for which there is evidence in the literature. This toolkit will be updated periodically as additional information becomes available.*



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Critical Care Services Ontario | March 2014

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Abbreviations

ACCM	American Academy of Critical Care Medicine
ACP	Advanced Care Planning
CACCN	Canadian Association of Critical Care Nurses
CCB	Consent and Capacity Board
CCCS	Canadian Critical Care Society
CCSO	Critical Care Services Ontario
CMPA	Canadian Medical Protection Association
ECFAA	Excellent Care for All Act
EOL	End-of-Life
HCCA	Health Care Consent Act
HHR	Health Human Resources
HQO	Health Quality Ontario
ICU	Intensive Care Unit
LHIN	Local Health Integration Network
PC	Palliative Care
PGT	Public Guardian and Trustee
OT	Organ and Tissue
QIP	Quality Improvement Plans
SARS	Severe Acute Respiratory Syndrome
SDM	Substitute Decision-Maker
SME	Subject Matter Expert

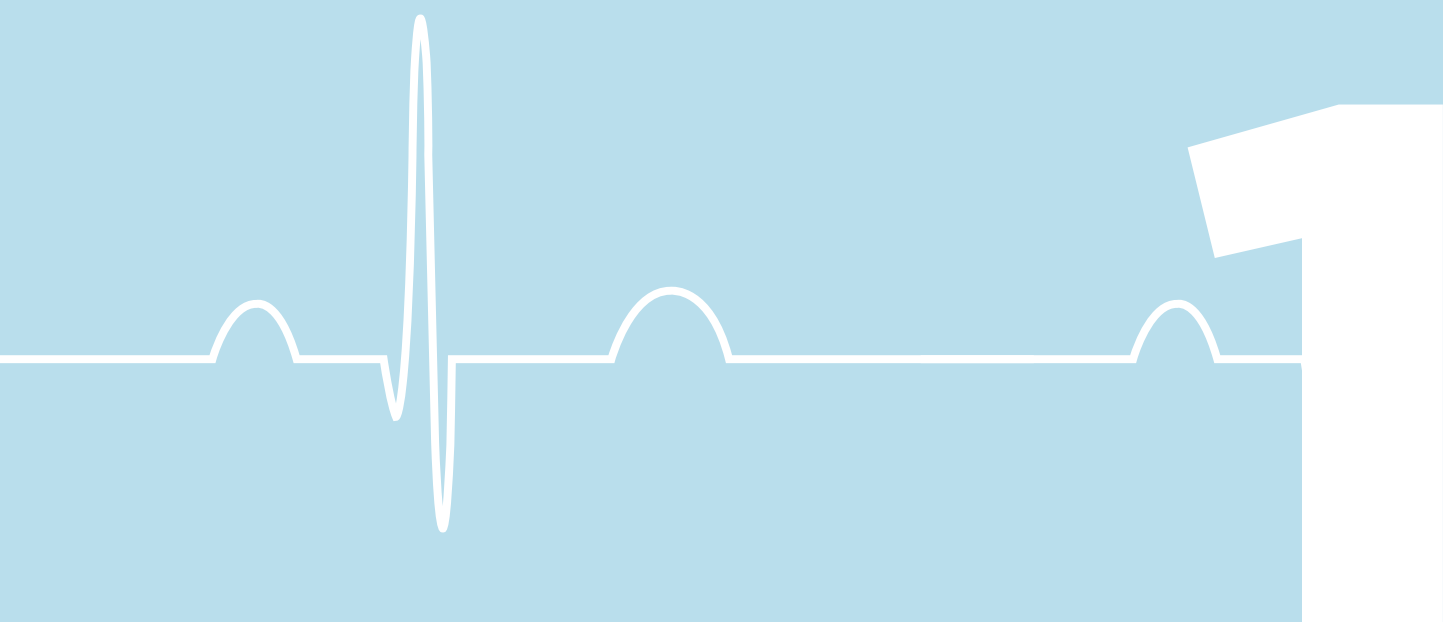
Definitions

Advance Care Plan (ACP)	Outlines patient wishes to guide medical care choices in the event they become incapable to make future decisions. ACPs are reflective of a patient's goals, values and beliefs and may outline a patient's choice for a substitute decision-maker. The specific wishes expressed in an ACP can be interpreted by the substitute decision-maker to make decisions for the incapable patient. ¹ An ACP can outline the kinds of treatments that should or should not be undertaken in the event of being incapable. ²
Advance Directive	Wishes, expressed verbally or in writing that describe future healthcare choices in the event of future incapacity, taking into account of patient goals, values and beliefs. ³
Health Practitioner	A member of a College under the Regulated Health Professions Act, 1991, a naturopath registered as a drugless therapist under the Drugless Practitioners Act or a member of a category of persons prescribed by the regulations as health practitioners. ⁴
Healthcare Team	Includes the multidisciplinary ICU team and any consulting specialty team involved in the care of the patient.
Levels of Care	<p>Level 1 Unit: Capable of providing services to meet the needs of patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with or without additional advice and support from a critical care team. Management may involve remote support provided by a Level 3 service.</p> <p>Level 2 Unit: Capable of providing service to meet the needs of patients who require more detailed observation or intervention including support for a single failed organ system, short-term non-invasive ventilation, post-operative care, patients “stepping down” from higher levels of care or “step ups” from lower levels of care. These units provide a level of care that falls between the general ward (Level 1) and a “full service” critical care unit (Level 3). Level 2 units do not provide invasive ventilator support.</p> <p>Please Note: Critical care units that provide invasive mechanical ventilation for a short period (for example ≤ 48 hours) but need to transfer those patients who require more long-term invasive ventilation to a Level 3 unit are considered Level 2.</p> <p>Level 3 Unit: Capable of providing the highest level of service to meet the needs of patients who require advanced or prolonged respiratory support, or basic respiratory support together with the support of more than one organ system. This is generally considered a “full service” critical care unit despite the fact some specialized services may not be available (e.g. dialysis). All Level 3 units are capable of invasive ventilator support.</p> <p>Please Note: For institutions that combine Level 2 and Level 3 type critical care service in one geographic area (i.e. unit), the unit designation reflects the highest level of care provided.</p>
Multidisciplinary ICU Team	Includes physicians, nurses, registered respiratory therapists, pharmacists, dieticians, physiotherapists, social workers, occupational therapists, ethicist, and spiritual care providers and any other team member working in the ICU.

Definitions continued on next page...

Definitions continued

Plan of Treatment	<p>a) is developed by one or more health practitioners,</p> <p>b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and</p> <p>c) provides various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of some treatments in light of the person's current health condition.⁵</p>
Potentially Life-Sustaining Treatment	Refers to all types of medical efforts that may be used in an attempt to support a patient through a potentially reversible life-threatening illness, including artificial ventilation, vasopressor/inotropic support, hydration and nutrition. The word "potential" is used to emphasize the fact that there exists no certainty that any treatment will be successful. Success rates vary widely between and within treatment types. ⁶
Standard of Care	The degree of care and skill which could reasonably be expected of a normal, prudent practitioner in similar circumstances. For example, the College of Physicians and Surgeons of Ontario (CPSO) has established Clinical Practice Guidelines meant to inform (rather than define) a standard of care. For cases where a physician may have breached the standard of care, the Court considers the standard of professional care and skill that might reasonably have been provided by a colleague in similar circumstances (www.cmpa-acpm.ca). ⁷
Substitute Decision-Maker (SDM)	A person with legal authority in a guardianship order, power of attorney for personal care or otherwise, as set out in the Health Care Consent Act (HCCA) to make decisions regarding proposed treatment for an incapable person. ⁸
Tool(s) 	A written or verbal resource used to assist health practitioners. The tools may be administered in various formats such as written questionnaires and brochures, checklists and interviews to guide physicians as well as patients/SDM in following the processes for appropriate decision-making and obtaining consent for critical care interventions.
Treatment	Anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan. ⁹



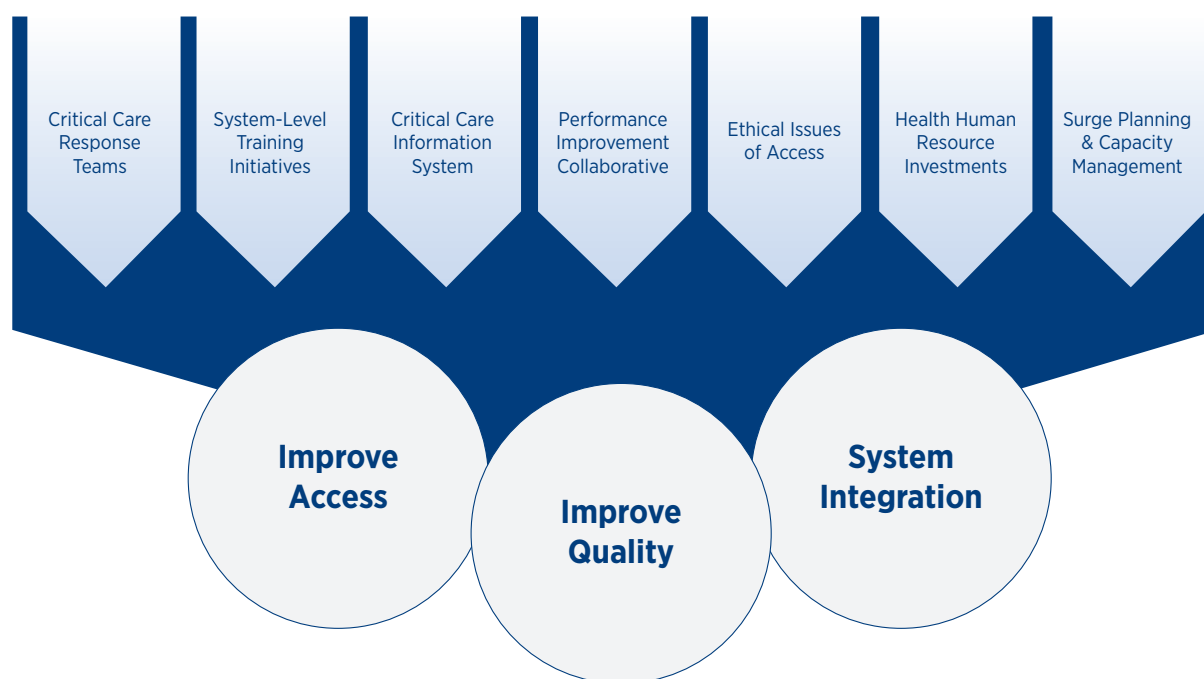
Introduction

Ontario's Critical Care Strategy

Following Ontario's SARS (Severe Acute Respiratory Syndrome) outbreak in 2003, the Ministry of Health and Long-Term Care (MOHLTC) assigned a group of system leaders to form the Ontario Critical Care Steering Committee. The Committee conducted a comprehensive review of the province's critical care services, which resulted in a report (2005) that set out the blueprint to transform Ontario's critical care services.

Following the report, the MOHLTC announced Ontario's Critical Care Strategy (January 2006), a seven-fold strategy to improve Access, Quality and System Integration (see Figure 1). The strategy has since expanded to incorporate broader program areas related to critical care including neurosurgery, trauma and burns, transplant, and chronic ventilation.

Figure 1. Ontario's Critical Care Strategy



Background

The decision to admit a patient to the Intensive Care Unit (ICU) or to withdraw potentially life-sustaining treatment is challenging due to scientific uncertainty, interpretation of the patient's expressed wishes or advance directives, the role of the substitute decision-makers (SDMs), ongoing advances in medical knowledge and technology, and the limited ability to accurately predict patient-specific healthcare outcomes. Deciding to use *potentially* life-sustaining treatments is determined by ICU teams who weigh inputs related to medical benefit (such as the need for ventilator and/or hemodynamic support), likelihood of patient survival, patient wishes, cultural and religious beliefs, values and goals (non-medical criteria). Further, the team must assess how the limits, uncertainties and progress of medical sciences should be taken into account in a dynamic clinical situation.

In recent years, the ethics sections of Canadian, American and European Critical Care Societies have issued position statements and proposed recommendations for the appropriate use of critical care services.^{10,11,12} These policies describe the goals of critical care provision; to support a patient through an acute, potentially reversible, life-threatening illness, while providing guidance on the medical diagnoses and criteria (physiological and hemodynamic) that require the specialized skills and technologies of an ICU.^{13,14} Additionally, at the provincial level, Surge Capacity Management Program and a Life or Limb Policy have been developed to ensure critically-ill patients have access to critical care services when needed. It is therefore fundamental for the front-line clinician to be knowledgeable about these policies and processes to help ensure they have addressed challenges *[in this case, related to access and consent]* to the best of their ability, and are in alignment with healthcare laws of Ontario and wishes and values of the patient.

Purpose of the Toolkit

This toolkit outlines the consent pathway that informs and guides decision-making amongst health practitioners, patients and families. It aims to support the development of appropriate treatment plans proposed by clinicians and consented to by patients or SDMs. In short, it will help ensure that the patient receives beneficial treatment in the right bed (to meet their care needs) at the right time.

This toolkit seeks to:

- Clarify the legal and ethical obligations embedded in the consent process
- Address the complex clinical challenges that arise in critical care
- Provide tools to enhance communication between health practitioners, patients, SDMs and family members at end-of-life (EOL) through consistent language

Alignment with ECFAA

The **Excellent Care for All Act (ECFAA)** includes a requirement for hospitals to develop annual Quality Improvement Plans (QIP) to outline the Aim, Measure and Change for quality initiatives across five dimensions: safe, effective, accessible, patient-centred and integrated care.¹⁵ Hospitals are required to submit their QIPs to Health Quality Ontario (HQO) to facilitate provincial comparison across a minimum set of quality indicators.

The *Critical Care Access and Consent toolkit* is a quality improvement effort that is aligned with ECFAA and can support the delivery of QIP in hospitals. Use of the toolkit, and integration of processes outlined herein will reflect the hospitals' commitment to deliver high quality care.

Informed Consent

Key to meeting one's ethical obligations to patients is to ensure that decision-making is aligned with the legal requirements for consent as outlined in the Health Care Consent Act (HCCA). In Ontario, the HCCA with some limited exceptions in the case of 'emergencies' requires physicians to obtain consent from a capable person. If the patient is incapable, his/her substitute decision-maker (SDM) provides consent to the proposed treatment which may include limitations on the use of life supporting measures.¹⁶

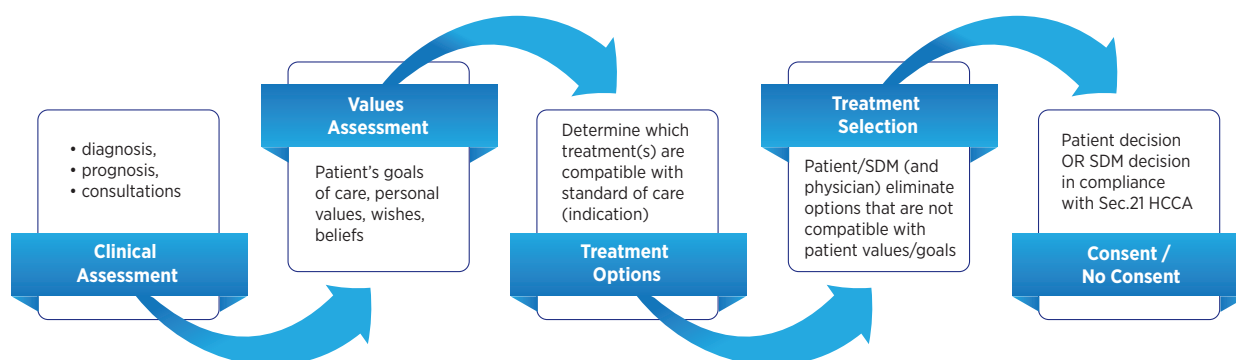
In other words, consent is legally required before providing treatment, unless extenuating circumstances apply (e.g. in emergencies). This is grounded in the ethical principle of autonomy which demands consideration of the person's rights in relation to their body and personal health information.

See Appendix A for excerpts from the HCCA, outlining the requirement for consent and providing the meaning of 'emergencies' where consent may not be obtainable in a practical manner.¹⁷ Health practitioners are encouraged to consult the Act in order to familiarize themselves with all the legislative requirements surrounding consent.

Process for Obtaining Informed Consent

The HCCA outlines requirements for obtaining informed consent (Figure 2 – Consent Pathway). This pathway outlines the steps that must be taken in order to meet the ethical and legal obligations when obtaining informed consent. This process ensures there are fewer errors in obtaining consent, resulting in treatment decisions that can benefit and are wanted by the patient.¹⁸ The pathway supports patient-centered clinical care reflective of the patient's values, wishes and beliefs, consistent with clinical knowledge and expertise.^{19, 20, 21}

Figure 2. Consent Pathway²²

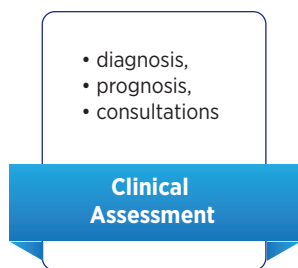


Source: Sibbald R, Chidwick P, Cooper A, Consent Pathway, Healthcare Consent Quality Collaborative. Date retrieved: 02/03/2013, URL: (<http://consentqai.ca/positions-interpretations/consent-pathway/>)²³



Step 1: Clinical Assessment

Step 1 - Clinical Assessment



A health practitioner must assess the patient's clinical issues, the diagnosis, prognosis and treatment options that are medically appropriate. This practitioner must have the skill, knowledge and expertise to render clinical decisions and is a "member of a College under the *Regulated Health Professions Act, 1991*."²⁴ **This practitioner is responsible for obtaining informed consent.**

If the practitioner determines that a patient is incapable of giving consent, they must identify a Substitute Decision Maker (SDM) and obtain consent from them. Even if there is an SDM, the physicians must include the patient (where appropriate) in discussions held with the SDM. There are various steps that can be followed if the patient or the physician disagrees with the involvement of the SDM. These are outlined in the CPSO policy '**# 4-05 Consent to Medical Treatment**.' The policy also sets out when and how a physician can obtain a patient's consent to treatment and what constitutes consent.²⁵

Addressing patients and their SDMs should be done thoughtfully and empathetically while providing a complete depiction of all potential treatment plans and recommendations for course of action. Explaining options simply, but thoroughly and addressing the patient's and SDM's concerns honestly can minimize conflict, open communication and expedite decision-making.

It is essential that documentation of the consent conversations and decisions between health practitioner and patient/SDM be noted in patient records. Consent to treatment may be implied or it may be specifically expressed. In Subsection 11 (4) of the HCCA, express consent is directly given, either orally or in writing. It is positive, direct, unequivocal consent, requiring no inference or implication to supply its meaning. Implied consent is consent that occurs when surrounding circumstances are such that a reasonable person believes that consent had been given, although no direct, express or explicit words of agreement had been uttered.

Excerpt from HCCA

Express or implied

(4) Consent to treatment may be express or implied. 1996, c. 2, Sched. A, s. 11 (4).

In order to participate in treatment decisions, capacity of the patient needs to be evaluated by the clinician. The patient is presumed to have the capacity to consent to treatment if they are able to:

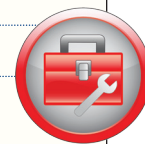
- **Understand the information that is relevant to making a decision about the treatment and;**
- **Reasonably appreciate the foreseeable consequences of a decision or lack of decision.**²⁶

It is important to note that 'the capacity' of the patient can change at any time and be different depending on the nature and complexity of the specific treatment decision. Therefore, determining the patient's ability to understand the nature and effect of the treatment should be part of an ongoing process.

Tools for step 1 [determining patient capacity, identifying an SDM and facilitating discussions with a patient] are outlined on the following pages.

1. Aid to Capacity Evaluation (ACE) – Form

Purpose of Tool	This tool enables physicians to adequately assess the patient's ability to provide consent, or assess whether a substitute decision maker (SDM) is required.
Intended Use	To be used during initial assessment of patient.
Source	Joint Centre for Bioethics – Aid To Capacity Evaluation (ACE) http://www.jointcentreforbioethics.ca/tools/documents/ace.pdf



Aid To Capacity Evaluation (ACE) - Form

Name of Patient: _____

Record observations which support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a checkmark.

1. Able to Understand Medical Problem:

YES [] UNSURE [] NO []

Observations: _____

2. Able to Understand Proposed Treatment:

YES [] UNSURE [] NO []

Observations: _____

3. Able to Understand Alternative to Proposed Treatment (if any):

YES [] UNSURE [] NO []

Observations: _____

4. Able to Understand Option of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):

YES [] UNSURE [] NO []

Observations: _____

5. Able to Appreciate Reasonably Foreseeable Consequences of Accepting Proposed Treatment:

YES ☐ UNSURE ☐ NO ☐

Observations: _____

6. Able to Appreciate Reasonably Foreseeable Consequences of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):

YES ☐ UNSURE ☐ NO ☐

Observations: _____

Note: for questions 7a/7b a "YES" answer means the person's decision is affected by depression or psychosis.

7a. The Person's Decision is Affected by Depression:

YES ☐ UNSURE ☐ NO ☐

Observations: _____

7b. The Person's Decision is Affected by Delusion/Psychosis:

YES ☐ UNSURE ☐ NO ☐

Observations: _____

Overall Impression:

Definitely Capable	[]
Probably Capable	[]
Probably Incapable	[]
Definitely Incapable	[]

Comments:

(for example; need for psychiatric assessment, further disclosure and discussion with patient, or consultation with family)

The initial ACE assessment is the first step in the capacity assessment process. If the ACE is definitely or probably incapable, considerable treatable or reversible causes of incapacity (e.g. drug toxicity). Repeat the capacity assessment once these factors have been addressed. If the ACE result is probably incapable or probably capable, then take further steps to clarify the situation. For example, if you are unsure about the person's ability to understand the proposed treatment, then a further interview which specifically focuses on this area would be helpful. Similarly, consultation with family, cultural, and religious figure and/or psychiatrist, may clarify some areas of uncertainty.

Never base a finding of incapacity solely on your interpretation of domain **7a** and **7b**. Even if you are sure that the decision is based on a delusion or depression, we suggest that you always get an independent assessment.

Time taken to administer ACE:_____ **minutes**

Date: Day:_____ **Month:**_____ **Year:**_____ **Hour:**_____

Assessor:_____

2. Criteria for Identifying High Risk Patients



Purpose of Tool	Use criteria outlined below, to identify patients who are at high risk of mortality.
Intended Use	If a patient is found to be at high risk of mortality, discussions about goals of care with the patient should commence as well as conversations determining if an SDM may be required in the near future.
Source	Heyland DK, Cook DJ, Rocker GM, et al.; Canadian Researchers at the End of Life Network (CARENET), Defining priorities for improving end-of-life care in Canada. CMAJ, 2010. DOI:10.1503/cmaj.100131.

CRITERIA FOR IDENTIFYING HIGH RISK PATIENTS

55 years or older with one or more of the following advanced chronic illnesses:

Chronic obstructive lung disease (2 of the 4 of: baseline PaCO₂ of ≥ 45 mmHg, *cor pulmonale*; respiratory failure episode within the preceding year; forced expiratory volume in 1 sec ≤ 0.5 L)

Congestive heart failure (New York Heart Association class IV symptoms and left ventricular ejection fraction $< 25\%$)

Cirrhosis (confirmed by imaging studies or documentation of esophageal varices and one of three conditions: a) hepatic coma, b) Child's class C liver disease, or c) Child's class B liver disease with gastrointestinal bleeding)

Cancer (metastatic cancer or stage IV lymphoma)

End-stage dementia (inability to perform all ADLs, mutism or minimal verbal output secondary to dementia, bed-bound state prior to acute illness)

OR

Any patient **80 years of age or older** admitted to hospital from the community because of an acute medical or surgical condition.

OR

You answer "No" to the **Surprise Question**: "Would I be shocked if this patient died in the next year?"

3. SPIKES: Sharing Information and Prognosis with Patients and Families



Purpose of Tool	Protocol for disclosing unfavorable information; 'breaking bad news' to patients.
Intended Use	The protocol (SPIKES) consists of six steps. The goal is to enable the clinician to fulfill his/her objectives during the interview when disclosing bad news: gathering information, transmitting medical information, providing support to the patient, and eliciting the patient's collaboration in developing a strategy or treatment plan for the future. Medical students who have been taught the protocol have reported increased confidence in their ability to disclose unfavorable medical information to patients.
Source	SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer, Walter F. Baile, Robert Buckman, Renato Lenzi, Gary Glober, Estela A. Beale, Andrzej P. Kudelka, <i>The Oncologist</i> 2000; 5:302-311; doi:10.1634

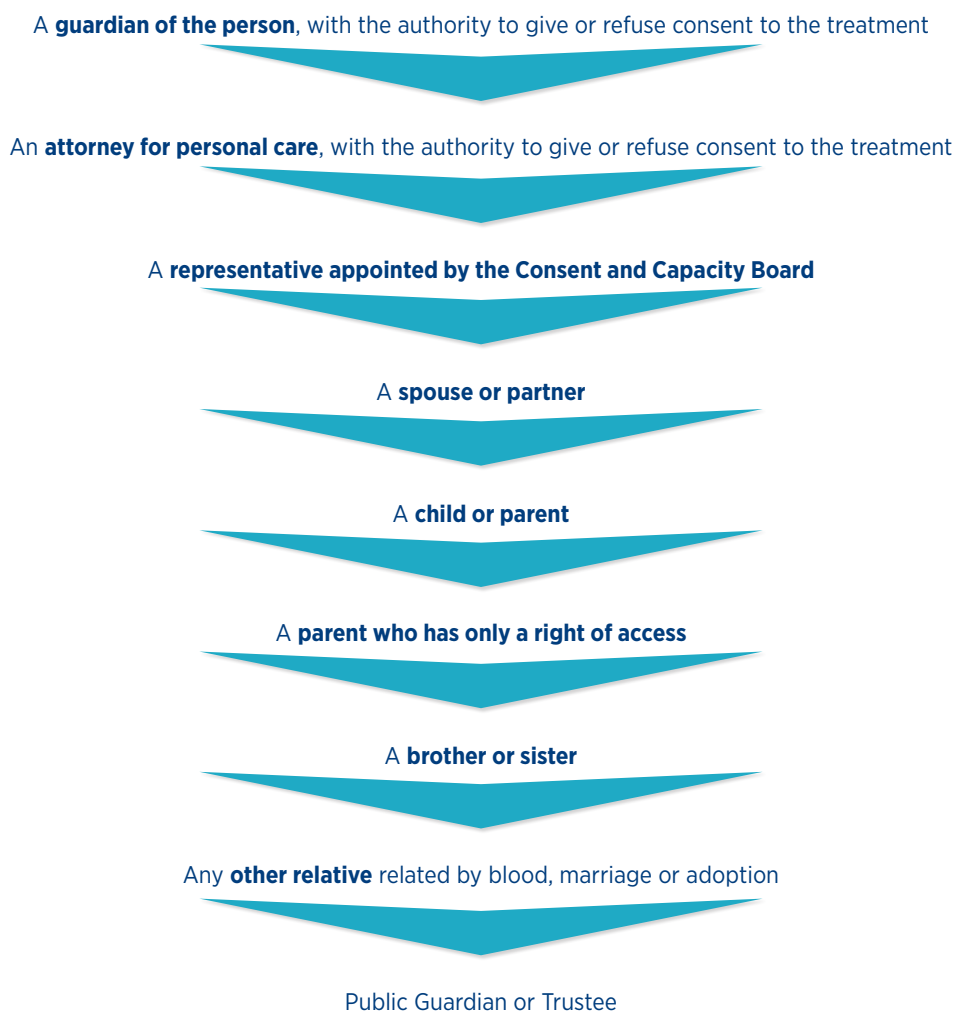
S	SETTING UP the interview	<ul style="list-style-type: none"> • Arrange for some privacy • Involve significant others of the patient (e.g. the SDM) • Consider involving a colleague (e.g. a nurse or a trainee, who has a good rapport with the patient) • Sit down and make eye contact
P	Assessing the patient or family member's PERCEPTION	<ul style="list-style-type: none"> • Ask how they perceive their medical situation, for example: • "What have you been told about your/your loved one's medical situation so far?" • "Tell me what the last year has been like for you/your loved one." • "What are your thoughts about the future?"
I	Obtaining the patient or family member's INFORMATION	<ul style="list-style-type: none"> • Find out what they want to know (not all individuals want full information): • "Are you the sort of person/people who want to hear all the details of their medical condition?"
K	Giving KNOWLEDGE and information	<ul style="list-style-type: none"> • Give small chunks of information in simple language, check periodically for their understanding • Acknowledge uncertainty when disclosing prognosis, e.g., give a range instead of one number
E	Addressing the patient or family member's EMOTIONS with empathic responses	<ul style="list-style-type: none"> • Identify patient or family members' emotions as they arise: • "I can tell you weren't expecting to hear this." • "It sounds like you are feeling overwhelmed by this." • Use exploratory questions if the patient or family member is silent: • "Could you tell me more about what is worrying you?" • "I want to make sure that if you have questions or things you are worried about, we can help"
S	STRATEGY and SUMMARY	<ul style="list-style-type: none"> • Summarize major areas discussed • Make a plan for the next meeting

4. Hierarchy of Substitute Decision Maker



Purpose of Tool	To determine SDM eligibility by ranking order as outlined in the Health Care Consent Act (HCCA).
Intended Use	The HCCA provides a hierarchy of persons who can provide substitute consent. The practitioner must obtain consent from the highest available substitute. Therefore, it is important that practitioners understand the hierarchy. The hierarchy, from highest to lowest is outlined in the tool below.
Source	http://consentqi.ca/projects/chelo/ link to Healthcare Consent Quality Collaborative, a Resource for Clinicians, Researchers, and Policy Makers http://consentqi.ca/wp-content/uploads/2013/02/SDMEnglish1.pdf (SDM Brochure)

RANK OF SUBSTITUTE DECISION MAKERS



Note: The substitute decision maker must be at least sixteen years old, be capable, willing and available to give consent. There can be multiple SDMs at same level and if so, they must agree.

KEY MESSAGES

STEP 1 Clinical Assessment

Consent is required from a capable patient prior to treatment and/or procedures, unless emergency circumstances apply where consent cannot be obtained in a practical manner.

Consent to treatment may be implied or it may be expressed either orally or in writing.

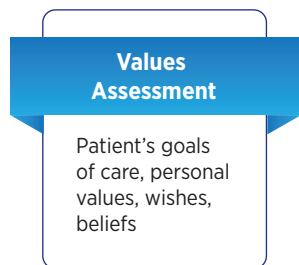
If the patient is incapable, a substitute decision-maker (SDM) is identified who provides consent to the proposed treatment, which can include, withholding or withdrawal of potentially life-sustaining treatment.

Ultimately, the patient or their SDM should receive a holistic overview of their medical condition and treatment options compliant with their values, wishes and beliefs.



Step 2: Values Assessment

Step 2 - Values Assessment



A member of the healthcare team must obtain information about the patient's values, wishes and beliefs, which is information necessary in providing patient centered care. All health practitioners can improve on this step by utilizing a number of emerging tools (e.g. values history sheet, values information forms, or checklists) to enhance capacity to get information related to what is important to the patient.²⁷

Information is gathered from a capable patient or SDM in the following manner:

- a) ***Advance directives:*** are prior expressed wishes in writing (e.g. a living will). *Advanced care planning (ACP)* is the process by which a person considers options about future health care decisions and identifies their wishes. These wishes help both SDMs and health practitioners understand the patient's wishes when developing and proposing a treatment plan. ACP can increase the quality of life for dying patients, improve the experience of family members, and decrease health care costs.^{28, 29, 30, 31}
- b) ***Previously-expressed wishes:*** In order to be applicable to treatment options, patient wishes must be specific to the situation. Consideration of such wishes acknowledges the autonomy and uniqueness of the individual patient, with particular respect to their values and preferences.
- c) ***Values, wishes and beliefs that inform the patient's decision-making:*** Values and beliefs are used to determine the patient's "best interest" when an incapable patient's wishes are not known.³² These must be balanced with consideration if benefits from the proposed treatment plan:
 - Will likely improve the patient's condition or well-being;¹
 - Will reduce or slow deterioration of the patient's condition;
 - Will outweigh the risk of harm and;
 - Will be equally or more beneficial than less-restrictive or less-intrusive treatments.
 (1996, c. 2, Sched. A, s. 21 (2).)

Many patients who develop incapacitating illness have not expressed clear treatment preferences. Therefore, substitute decision makers are asked to make judgments about what treatment is most consistent with the patient's beliefs and values. SDM's may struggle with such decisions and often need assistance in working through and identifying their loved ones' beliefs and values relevant to medical decisions.

Tools for Step 2 [capturing patient beliefs and values, soliciting SDM's decisions, using plain language with patients] are outlined on the following pages.

¹ As per Ontario case law, "Well-being" includes considerations of quality of life, personal perceptions of dignity, physical health and levels of pain and distress.

5. Patient Value Statement



Purpose of Tool	To help health practitioners ask the appropriate questions and ensure they are aware of a patient's values, wishes and beliefs when determining care plans.
Intended Use	Try to complete the form within 24 hours of admission. Patient Value Statement can be useful when Advance Directive is not available.
Source	Linda Nusdorfer, Riding the Waves of Patient/Family Values and Beliefs before and at the End of Life, University Health Network http://www.caccn.ca/en/pdfs/Session%204E%20Riding%20The%20Waves.pdf

Patient Value Statement

A patient value statement is an important tool as part of the process in determining quality of life decisions. Understanding the patient's values is essential when determining treatment plans and making quality of life decisions. Consider these questions before determining treatment plans.

- What family/friend supports exist for the patient?

- What is the patient/SDM's understanding of their illness and prognosis?

- How do they feel about aggressive treatment options and what are their goals of care?

- What are the religious considerations/beliefs of the patient?

Ensure that patient/SDM discussion and decisions are clearly documented in patient's medical records

6. Values Information Sheet



Purpose of Tool	To capture patient values, wishes and beliefs.
Intended Use	Within the first 72 hours of patient encounter. This approach seeks to constantly improve decision-making by minimizing common errors between teams, patients and substitute decision-makers.
Source	http://consentqi.ca/projects/chelo/

ChELO (Checklist for Meeting Ethical & Legal Obligations) For Patients in Intensive Care **Values Information Sheet (VIS)**

Patients Full Name: _____

Prefers to be called: _____

**Preferred language/
Communication Preference:** _____

Occupation: _____

Favorites:

Movie _____
 TV Show _____
 Book _____
 Music _____
 Sport _____
 Colour _____
 Food(s) _____
 Pet(s) _____
 Quote/Saying _____

Place Photo Here

Activities/Hobbies

Achievements of which they are proud:

Continued on next page...

How has he/she coped with stressful situations in the past?

What would the patient identify as his/her biggest worry/concern/fear?

What are his/her hope/dreams/desires? Other things I'd like you to know about them:



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7. The Facilitated Values History

Purpose of Tool	This tool can be used to elicit SDM's decisions using specific actions and suggested language to address barriers inhibiting decision making.
Intended Use	The seven behaviours are used to elicit actions and provide language that clinicians can use to help SDMs make treatment decisions (which can seem difficult) on behalf of the patient.
Source	Scheunemann LP, Arnold RM, White DB. The Facilitated Values History, Helping Surrogates Make Authentic Decisions for Incapacitated Patients with Advanced Illness, The American Journal of Respiratory and Critical Care Medicine, 2012 Sep 15;186(6):480-6.doi: 10.1164/rccm.201204-0710CP. Epub 2012 Jul 19. http://ajrccm.atsjournals.org/content/186/6/480.full

Behaviour	Specific Actions	Examples
Attend to surrogates' emotions	NURSE mnemonic Enlist interdisciplinary support	N -ame the emotion: "You seem upset." U -nderstand the emotion: "This is such a hard thing to go through." R -espect the family: "You are doing a wonderful job of representing your mother." S -upport the family: "How are you and your family doing?" E -xplore the emotion: "Tell me more about why you feel that way."
Help surrogates understand their contribution to decision making	Explain that decisions are value laden. Reduce projection biases	"Different people feel very differently about what kind of treatments they would accept if they became very sick. We hope you can help us understand what your dad's views are." "Our goal should be to honor your mother by trying to understand what she would choose if she were sitting here." "Sometimes it is really hard to separate what you might want for your father from what he might choose for himself, but it is really important to try."
Understand the patient as a person		"Tell me what your dad liked to do before he came in the hospital." "As he was getting sicker, what did he worry about the most?" "What was she like?"
Explore specific values and value conflicts	Discuss the range of relevant values Explore value conflicts	Explore attitudes about physical/cognitive impairment, social functioning, religious beliefs, prolonged use of life support Explore advance directives Point out values in tension/conflict Explore which values would be most important if all could not be fulfilled simultaneously
Summarize the values relevant to the decision		"We have covered a lot in this conversation. Can I tell you what I've heard? It sounds like your brother valued being able to take care of himself. His work as an editor was important to him. He would not want to live in a nursing home under any circumstances, and wouldn't want to be kept alive by machines in the long term, but would accept life support temporarily if there was a reasonable chance he could get back to living independently and working as an editor. Have I missed anything?"

Continued on next page...

Behaviour	Specific Actions	Examples
Bridge between values and treatments	Demonstrate bridges	<p>For “hypothetical patients”: “If your mother felt that living as long as possible regardless of quality of life was the most important thing, then it would be most appropriate to keep her on the breathing machine, place a feeding tube, and begin to explore options for a place where she can remain on a ventilator long term. If she felt that the treatments she is receiving would not have enough of a chance of restoring her to an acceptable quality of life, then we should stop these invasive treatments and begin to focus on maximizing her comfort and the other things that would be important to her during this time.”</p> <p>Based on the patient's values: “Based on what you have told me about your Mom, I recommend a trial of being on the ventilator to see if things get better quickly. If they don't, then we should focus on keeping her comfortable and remove her from the ventilator.”</p>
Give “permission” to follow the patient's wishes	<p>Express empathy Address moral concerns</p> <p>Share social norms</p>	<p>“These decisions are hard. You are doing a really good job advocating for your mom.”</p> <p>“I can see this is upsetting.”</p> <p>“Sometimes people are worried about whether it is okay to make these decisions.</p> <p>Are you concerned about this?”</p> <p>“One important way to respect your father as a person is to make decisions that fit with his values.”</p> <p>“Some families are concerned that stopping life support isn't allowed. In fact, it's common in intensive care units to stop treatments when it's clear that they aren't going to achieve the patient's goals.”</p> <p>Provide patient-centered recommendations</p>

The Role of Advance Care Planning (ACP)

Advance Care Planning (ACP) 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.”³³

Opportunity for ACP can be taken with those patients at the time of admission to the emergency department and/or hospital wards, with:

- Advanced stages of chronic life-threatening diseases;
- Cared for and admitted from long-term care facilities;
- Severe acute illness with likely future deterioration; and/or
- High likelihood of needing future critical care services.

All patients should be proactively asked about advance care plans. To meet ethical obligations, critical care teams should ask about ACP from the capable patient or SDM of incapable patients *before* decisions for potentially life-sustaining treatments are considered.

This will ensure treatment options are informed by prior expressed wishes. In some cases, these discussions may need to occur repeatedly over time and periodically re-explored to reflect changes in a patient's state of health, values and goals. It is important to explore the meaning and applicability of previously expressed wishes in the context of new and emerging clinical situations and possibilities. This dialogue can inform potential crisis situations when patients are rapidly deteriorating and time is limited.

An advance directive is a form of advance care planning; a communication prepared by the patient indicating their wishes in the event of an illness or injury that leaves them unable to communicate. The advance directive may also designate the SDM as per a patient's Power of Attorney for Personal Care, otherwise the HCCA hierarchy applies. It is important to note that these wishes do not constitute consent or refusal to treatment.

For patients who require useful tools regarding advanced care planning, they can be directed to the Advanced Care Planning Toolkit located on the Speak Up website:

<http://www.advancecareplanning.ca/making-your-plan.aspx>

8. Patient Advanced Care Planning Questions in Plain Language



Purpose of Tool	To identify patient's goals of care and advanced care directives by asking questions in an easy to understand manner.
Intended Use	Using plain language to ask difficult questions about advance care planning enables communication that is easier to understand.
Source	Adapted from Speak Up website: http://www.advancecareplanning.ca/making-your-plan.aspx

Asking patients about their own advance care planning should target the following four factors:

1. Patient's understanding of the prognosis of the underlying co-morbidities of disease
2. Patient's consideration for aggressive life-support interventions (i.e. CPR, ventilation)
3. Patient's designation of a SDM
4. Patient's consideration of what may happen if their health deteriorates (i.e. Loss of independence)

Suggested Patient-focused language:

1. If your health becomes worse, despite current or proposed treatments, do you understand other complications you may develop?
2. Do you understand that if you get worse and wish to have aggressive life support this could involve CPR, with the possibility of breaking your ribs, as well as having tubes down your throat, attached to a breathing machine, being unconscious and having your loved ones make decisions about your ongoing care?
3. Have you chosen someone to help you or make decisions for you if you can't make choices yourself?
4. Have you considered being unconscious on life support and requiring someone else having to make decisions about limiting or removing life-supporting measures?

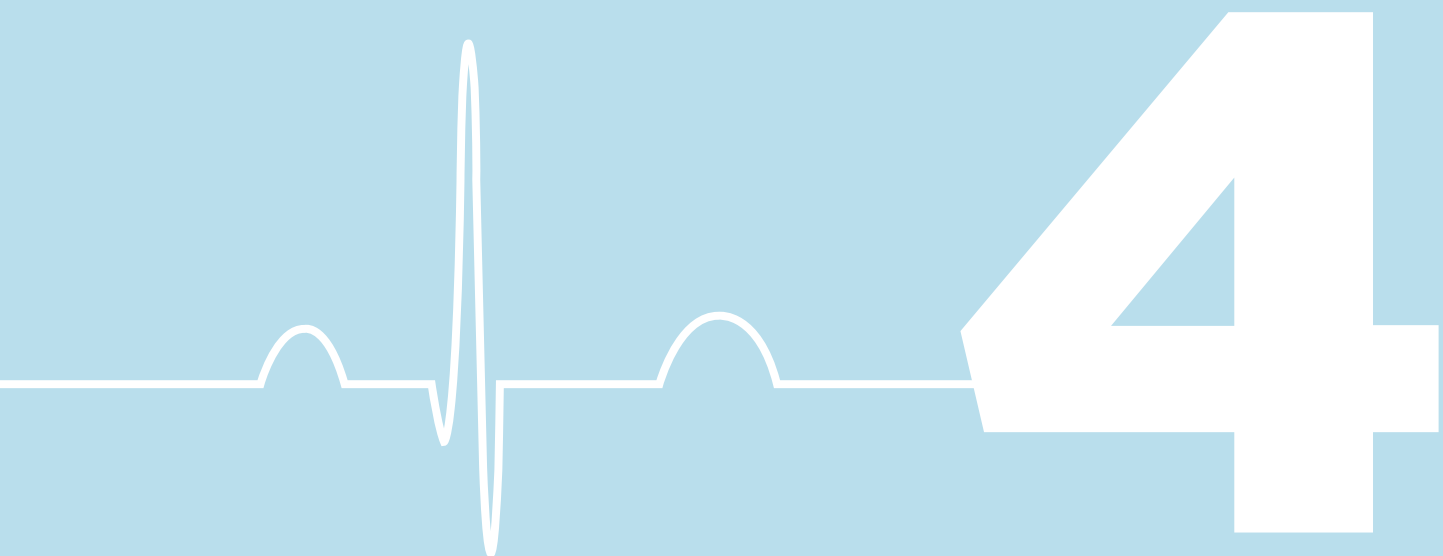
KEY MESSAGES

Step 2 Values Assessment

Treatment plan must be formed with information about the patient's values, wishes and beliefs (sometimes found in advance directive or through speaking to the patient).

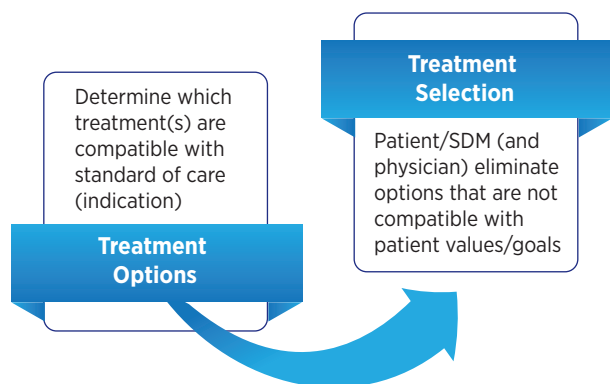
Advanced care planning is a process (not a one-time event) since the patient's health status may change anytime and this may require changes to his/her advanced care plan.

Advance care plans are directions to SDMs. SDMs need assistance in identifying and working through the sometimes conflicting values relevant to their loved one's medical decisions near end of life.



Steps 3 and 4:
Treatment Options and Selection

Steps 3 and 4 – Treatment Options and Selection



Health practitioners are responsible for proposing treatment. In this step, the clinical options must be proposed to the patient or SDM (if the patient is not capable) that are in line with their values, wishes and beliefs.

Treatment options may be informed by ACP, where information about prior expressed wishes of the patient may be available. The proposed treatment should be specific and appropriate to the condition. It is not necessary or justified to

offer treatment that is not likely to benefit the patient. When uncertainty exists, it may be helpful to obtain additional information or opinions, including multidisciplinary consultation to clarify medical and patient goals and options.

Prognostic disclosure is an important component of End of Life (EOL) communication and decision-making, yet occurs infrequently amongst seriously-ill hospitalized patients.³⁴ There are multiple clinical prediction rules for mortality during or after ICU care.³⁵ While none of these tools are predictive for individual patient cases, they can inform the discussion with the patient and/or SDM.¹¹

The appropriate treatment plan should be proposed to the patient or SDM. **It is the right of a capable patient or their SDM to refuse treatment decisions, despite their apparent benefit.**

In short, the practitioner presents all relevant information for a person to inform a decision about treatment. Documentation of conversations and decisions between the practitioner and patient/SDM should be retained.

There are important considerations for how to communicate a proposed treatment plan. For example, asking a patient “*Would you want to go on life support?*” or “*Do you want us to do everything?*” does not meet the legal and ethical standards of informed consent because it does not obtain information about values, wishes and beliefs from the patient or SDM.^{36, 37, 38} Further, this approach perpetuates a common misconception for life-sustaining treatment where patients or substitute decision-makers could agree to a plan of treatment which offers minimal benefit.

Tools for Steps 3 and 4 [facilitating End of Life discussions, checklist when proposing treatment plan] are outlined on the following pages.

11 For additional information regarding prognostic indices please see Yourman, Lindsey C., et al. “Prognostic indices for older adults.” JAMA: The Journal of the American Medical Association 307.2 (2012): 182-192.

9. Checklist for Health Practitioner Proposing the Treatment Plan



Purpose of Tool	This checklist can act as a guide for conversations regarding EOL discussion and treatment plans.
Intended Use	This tool acts as a reminder to ensure that all necessary information is discussed regarding proposed treatment plans so patients/SDMs are able to make informed decisions
Source	Critical Care Services Ontario (CCSO)

Checklist for Practitioner Proposing the Treatment Plan

When discussing EOL decisions with a patient or their SDM, it is important to present the following information:

- ☐ Nature of the treatment
- ☐ Expected benefits of the treatment
- ☐ Material risks of the treatment
- ☐ Material side effects of the treatment
- ☐ Alternative courses of action
- ☐ Likely consequences of not having the treatment

Note: Document discussions and decisions in patient's medical records

Withdrawing/Withholding Life-Sustaining Treatment

The CPSO Policy “#1-06 Decision making for the end of life” articulates relevant principles that apply to critical care and EOL decision-making.³⁹ Other organizations, such as the Canadian Critical Care Society (CCCS), American Academy of Critical Care Medicine (ACCM) and Canadian Association of Critical Care Nurses (CACCN) have all proposed various positions on end-of-life decision-making.

The CPSO policy aims 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”.

The challenge arises when proceeding with withholding or withdrawing of life supporting measures, under the principle of lack of benefit to the patient, is in conflict with the values and beliefs of the patient or family. Health practitioners may undergo moral distress over what is perceived to be futile therapy. Minimizing this distress is necessary as to limit emotionally charged conversations of withdrawing/withholding life-sustaining treatment with a patient and their family to avoid disagreement and retrograde decision making.

Some strategies, when integrated into the practice of critical care, can prevent and avoid division between patients and families, and health practitioners.⁴⁰ These include:

- Awareness of both the accuracy and limitations of prognostication in acute severe illness and chronic debilitating illnesses including chronic critical illness;
- Critical care practitioner participation in ward care and decision-making regarding realistic goals of intensive care through outreach teams;
- Effective communication with families including structured family meetings;
- Advance agreements for time-limited trials of intensive care, and;
- Augmented availability of various disciplines including spiritual care and bioethicists for assisted family communication.

Further, integration of palliative care principles and practices are essential to modern critical care, and should be introduced earlier in the patient care journey.

Health practitioners should have a clear understanding of the role of proxy decision-makers and best interests of the patient. Lack of clarity of the concepts encompassed in these two terms is frequently the source of less ideal and prolonged EOL decision-making. Current best practice in approaching end of life decision-making in critical care includes the principles outlined in the relevant CPSO policy as well as the emerging trends in scope and practice of critical care outlined in professional organization recommendations.^{41, III}

III There are potentially life-sustaining therapies where the decision to deploy has conventionally been in the domain of health care workers using a strictly physiologic approach to calibrating usefulness, for example surgery, chemotherapy. The differences between the readily apparent but often emotion-based decision to use an intensive care bed, CPR or ventilator in contrast to the more physiologically-based decisions to conduct or offer surgery or can be a source of ongoing distress and paradox for health care workers. This paradox over these differences continues to be a motivator in many people for change in the current approach to the use of intensive care resources.

10. Strategies for Improving End-of-Life Communication in the ICU



Purpose of Tool	To communicate best options of treatment plans or withholding/withdrawing treatment with patients and their families.
Intended Use	The tool can help facilitate effective communication (and avoid tension) between the clinician and family members during the patient's stay in the ICU.
Source	Truog, Robert et al. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. Critical Care Medicine: Volume 36(3), March 2008, pp 953-963.

Strategies for Improving End-Of-Life Communication in the ICU

1. Communication skills training for clinicians

2. ICU family conference early in the ICU course

Evidence-based recommendations for conducting family conference:

Find a private location

Increase proportion of time spent listening to family
Use "VALUE" mnemonic during family conferences

V
A
L
U
E

alue statements made by family members.
cknowledge emotions.
isten to family members.
nderstand who the patient is as a person.
licit questions from family members.

Identify commonly missed opportunities

Listen and respond to family members.
Acknowledge and address family emotions.
Explore and focus on patient values and treatment preferences.
Affirm non-abandonment of patient and family.

Assure family that the patient will not suffer

Provide explicit support for decisions made by the family

Additional expert opinion recommendations for conducting family conference:

Advance planning for the discussion among the clinical team

Identify family and clinician participants who should be involved.
Focus on the goals and values of the patient.
Use an open, flexible process.
Anticipate possible issues and outcomes of the discussion.
Give families support and time.

3. Interdisciplinary Team Rounds

4. Availability of palliative Care and/or ethics consultation

5. Development of a supportive ICU culture for ethical practice and communication

The Role of Palliative Care (PC)

The World Health Organization defines **Palliative Care (PC)** as an “*approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness.*”⁴²

PC is highly relevant for critically-ill patients with a high risk of mortality, who often experience significant pain and other unpleasant symptoms as well as psychological and spiritual distress during their admission.

PC aims to:

- **Provide pain and symptom relief;**
- **Support patients who are experiencing psychological and spiritual distress;**
- **Facilitate communication about diagnosis, prognosis, and goals of care; and**
- **Counsel family members of dying or recently deceased patients.**

On a practical level, ICU clinicians can routinely consult PC services (if available) in their hospital to co-manage patients at high risk of death or who have refractory symptoms. Commonly, the ICU team is capable of and routinely provides measures to relieve pain and discomfort. It can be helpful to have a comprehensive understanding of PC principles which include:⁴³

- **Education for staff about the principles of PC;**
- **Local champions to role-model PC at the bedside;**
- **Academic detailing of individuals to identify and overcome local barriers to PC;**
- **Feedback of local unit-level performance indicators;**
- **System supports, such as standardized order sets, for patients being withdrawn from life support.**^{44, 45}

Palliative Care for Critically-Ill Patients Outside the ICU

ICU clinicians have an opportunity to assess many patients before they require life support. Pre-ICU consults can allow better communication with the patient, and may result in a change in the philosophy of care to a less aggressive, more palliative approach. In Canada, 10 per cent of pre-ICU consults result in a change in resuscitation order.^{46, 47} Whenever an ICU consult results in a change in resuscitation order, the ICU clinician should verify goals of care with the Most Responsible Physician (MRP) and consider consulting PC or ordering comfort medications if appropriate and aligned with the goals of care.

PC can also be helpful for patients with terminal illnesses who are being discharged from the ICU. Often, these patients were originally admitted to the ICU with curative goals of care, but these goals changed over the course of the admission to focus on comfort. PC can help establish continuity of care, address symptom issues, and support family members as they grieve for the anticipated loss of their loved one.

Aggressive care can lead to patients experiencing a lower quality of life;⁴⁸ bereaved family members with higher rates of depression and anxiety;⁴⁹ healthcare workers experiencing higher rates of emotional burnout;⁵⁰ and costs to the healthcare system being higher⁵¹ and palliative care offers a viable alternative; does not shorten life and uses comfort medications.^{52, 53, 54}

KEY MESSAGES

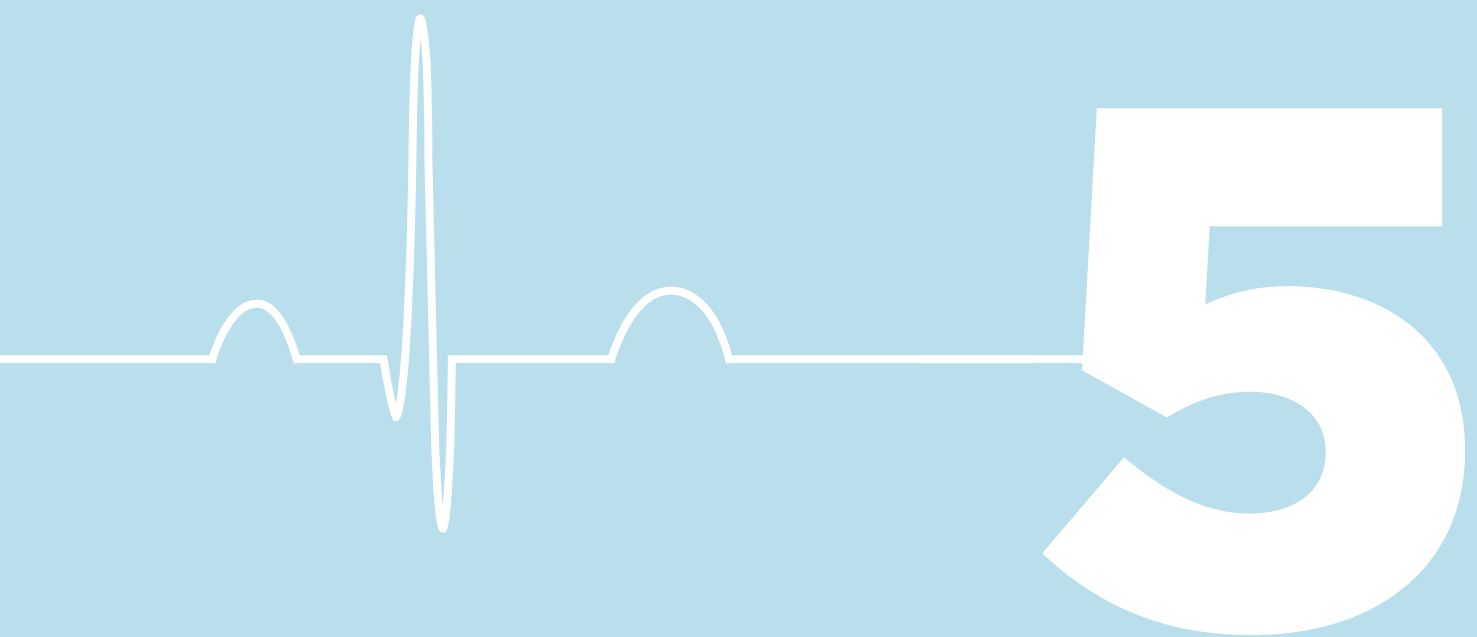
Step 3 & 4 **Treatment Options and Selections**

Health practitioners propose treatment plans.

Health practitioners must be aware of the patient's values, wishes and beliefs and, consider the patient's best interests when proposing withdrawing life-sustaining treatments.

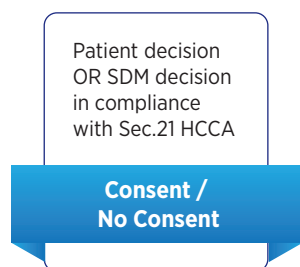
Early introduction of palliative care and spiritual care support to patients can facilitate end-of-life decision-making. Palliative care offers a viable alternative, does not shorten life and uses comfort medication.

Physicians have the obligation to secure consent and patients have the legal right to either consent to or refuse treatment. Focused and ongoing conversations therefore are necessary with patients/SDMs in order to minimize conflict.



Step 5: Consent / No Consent

Step 5 – Consent / No Consent



A health practitioner's professional responsibility requires them to propose a treatment plan which includes knowledge of the patient values, wishes and beliefs. The role of the patient or SDM is to provide consent or refusal to this proposed treatment plan. In other words, the practitioner determines what is clinically indicated and with consideration of the patient's values, wishes and beliefs, proposes a treatment plan. If potentially life-sustaining treatment falls outside the standard of care, there is no obligation to propose such treatment even if the patient values and wishes are to the contrary.

Situations may arise where the patient's wishes would require potentially life-sustaining treatments with risk that would outweigh any chance of benefit. In these situations, a practitioner proposes the treatment plan they think is appropriate, while meeting ethical and legal obligations and seeks to obtain consent. If patients (or their SDMs) are not in agreement with the treatment plan proposal to withhold or withdraw treatment, this can be brought to the **Consent & Capacity Board (CCB)**.

To avoid potential conflict around decision making, it is important to recognize the individual with the rights to make a decision. As stated earlier in the toolkit, when a patient is deemed to not have the capacity to make their own care decisions, a substitute decision maker (SDM) is required. The HCCA sets out the hierarchy of SDMs (see tool 4) to ensure that the appropriate proxy-decision maker is assigned. It requires that they be willing, available and capable with respect to the treatment decision for which consent is sought (HCCA 1996).

Role of the Consent & Capacity Board (CCB) of Ontario

The **Consent & Capacity Board (CCB) of Ontario** is an independent legal tribunal created to address questions around the application of the principles of consent and capacity as governed by the Health Care Consent Act (HCCA). It can respond to the concerns of SDMs and those of physicians. The CCB can hear disputes where there is disagreement between a practitioner and SDM about the prior expressed wishes or the best interests of the patient (and consent cannot be obtained).

The Board has the authority to hold hearings to deal with a number of matters including:

- A review of an individual's capacity to make decisions about health treatment, personal assistance services, or admission to a long-term care facility,
- Consideration of the appointment of a representative to make treatment decisions for someone who is incapable of making their own decisions,
- Consideration of a request for directions regarding prior capable wishes,
- Consideration of a request for authority to depart from prior capable wishes.

When a health practitioner **cannot** obtain consent for the treatment plan, they can file a **Form G** to initiate a hearing with the CCB. The CCB acts as a neutral third party to adjudicate the SDM's compliance with the legal principles of substitute decision-making as outlined in s. 21 of the HCCA.

When an application is made to the CCB, the proposed treatment plan is assumed to fall within the standard of care. Thus, proposed treatments should not fall outside the standard of care, as the CCB tribunal has

no jurisdiction to determine the medical standard of care. The physician has the option of contacting the Canadian Medical Protection Association (CMPA) if there is uncertainty about how a proposed treatment plan falls under the standard of care, prior to considering an application to the CCB.

While many disagreements with SDMs do not result in the need for a hearing, it is still entirely appropriate to file a Form G to convene a hearing where disagreement to consent for providing or withholding treatments exist. Before a hearing is triggered, all available approaches to resolve the dispute should be exhausted (e.g. second medical opinions, mediation, communication strategies, bioethics consultations, hospital policies and/or exploring patient transfer). Applications to the CCB should not be considered a failure of communication and an application itself does not necessarily entail a hearing. Like any judicial process applications are often resolved during the process or just prior to when the hearing is convened.

If a decision has been reached to apply to the CCB, it is important for physicians to meet all legal and ethical obligations related to the consent process. A checklist stemming from the HCCA has been developed for practitioners to check they have met their ethical and legal obligations prior to contacting the CCB (**See Tool 12**). Ensuring these requirements can promote a timely process and response for the patient.

Depending on the urgency of the case, the CCB can be convened anywhere from the same day to a maximum of seven days (except where all parties agree on another date).⁵⁵ Since 1996, there have been approximately 30 Form G's filed and decisions written.^{IV} Typically, a CMPA lawyer represents the practitioner at the hearing. The SDM may also retain a lawyer. The patient will also have independent council appointed by the Office of the Public Guardian and Trustee. The CCB process is unique to Ontario and physicians have found it “*worthwhile, patient-centered, orderly, process-oriented and efficient approach for resolving end-of-life conflict*” and determining best interest.⁵⁶

Like other judicial processes, CCB hearings have no set duration and the board will thoroughly explore each party's position before adjudication. Team members may be asked to provide testimony or evidence at these hearings. The Board may also ask to visit the patient. When hearing adjourns, the Board will provide a decision within twenty-four hours. If the decision is that the SDM is not compliant with the section 21 then the SDM is ‘ordered’ to provide consent to the proposed treatment plan. If the SDM has no intention of compliance, the next person on the hierarchy is consulted. If no SDM is willing to provide consent to the proposed treatment plan, the Public Guardian and Trustee (PGT) will be consulted. The role of the PGT is to comply with consent order. That is, they are legally obligated to consent to the proposed treatment. If the SDM wishes to appeal CCB decision, they must make an application to the Ontario Superior Court of Justice within 7 days. Reasons for the CCB decision are written at the request of any party at the hearing. These documents are public documents and can be found at www.CanLII.org.

Information sheets and the appropriate application forms can be obtained by contacting the Board and/or visiting their website at www.ccboard.on.ca

Tools for Step 5 [when to contact CCB and final checklist] are outlined on the following pages.

IV Please refer to Appendix B – Summary of Findings with the CCB.

11. Checklist for when to involve the Consent & Capacity Board



Purpose of Tool	This checklist can guide practitioners in identifying when to involve the CCB.
Intended Use	The CCB is an independent legal tribunal created to address questions around the application of the principles of consent and capacity as governed by the HCCA. It can respond to the concerns of SDMs and those of physicians, and can hear disputes where there is disagreement between a practitioner and SDM about the prior express wishes or the best interests of the patient.
Source	http://www.ccboard.on.ca/scripts/english/aboutus/index.asp

Checklist for when to involve the Consent and Capacity Board

The board has the authority to hold hearings to deal with the following matters, related to consent issues outlined in the HCCA.

- ☐ Review of patient's capacity to consent to treatment, admission to a care facility or personal assistance service
- ☐ Appointment of a representative to make decisions for an incapable person
- ☐ Request to amend or terminate the appointment of a representative
- ☐ Review of a decision to admit an incapable person to a hospital, psychiatric facility, nursing home or home for the aged for the purpose of treatment
- ☐ Request from a SDM for directions regarding wishes
- ☐ Request from a SDM for authority to depart from prior capable wishes
- ☐ Review of a SDM's compliance with the rules for substitute decision making

Note: Over 80 percent of applications to the CCB involve a review of a person's involuntary status in a psychiatric facility under the Mental Health Act, or a review under the Health Care Consent Act of a person's capacity to consent to or refuse treatment.

12. Checklist for meeting ethical and legal obligations for patients in the ICU



Purpose of Tool	To help practitioners understand their obligations and check that they have followed the necessary processes in obtaining informed consent from a patient.
Intended Use	To be used within 72 hours after a patient arrives in the ICU. The checklist empowers teams and the approach seeks to improve decision making by minimizing common errors between teams, patients and substitute decision makers.
Source	A sample from the William Osler Health System is provided below.

ChELO (Checklist for Meeting Ethical & Legal Obligations) For Patients in Intensive Care

DOCUMENT PATIENTS CAPACITY

- | | |
|---|--|
| 1. Document patient's capacity/incapacity | Yes <input type="checkbox"/> No <input type="checkbox"/> |
|---|--|

EXPLAIN SUBSTITUTE DECISION MAKER INFORMATION

- | | |
|--|--|
| 2. Identify the legally correct SDM. (See SDM brochure for hierarchy)
Contact information | Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 3. Give SDM <i>SDM Brochure</i> and <u>explain</u> role (See SDM Brochure) | Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 4. Give SDM <i>Family Information ICU Brochure</i> | Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 5. Give SDM <i>VIS (Values Information Sheet)</i> | Yes <input type="checkbox"/> No <input type="checkbox"/> |

COLLECT PATIENT INFORMATION

- | | |
|--|--|
| 6. Ask SDM if patient's wishes were written? (e.g. living will) | Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 7. Ask SDM about prior expressed wishes of patient.
<i>"Did you ever speak about this kind of situation with the patient and what did he/she say?"</i> | Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 8. Ask about values and beliefs of the patient?
<i>"What is important to the patient?"</i>
<i>"Tell me what kind of person was he/she?"</i>
<i>"Did he have religious commitment?" "How does s/he practice it?"</i> | Yes <input type="checkbox"/> No <input type="checkbox"/> |

Once the checklist is complete, you are now ready to begin discussions about treatment plans.



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KEY MESSAGES

Step 5 Consent/No Consent

Situations where the health practitioner cannot obtain consent from an SDM, which he/she thinks are in the best interest of the patient, can be brought to the Consent & Capacity Board (CCB).

Before a hearing is triggered, all available approaches to resolve the dispute should be exhausted (e.g. second medical opinions, mediation, communication strategies, bioethics consultations, hospital policies and/or exploring patient transfer).

It is the right of a capable patient or their SDM to refuse treatment decisions, despite their apparent benefit.

Organ and Tissue Donation and Critical Care

Organ and Tissue (OT) donation is an important topic for critical care because ICUs have a higher mortality rate than other units in the hospital, thereby raising the frequency of opportunities for OT donation. Recognizing the value of OT donation, a value-positive approach to OT donation has been adopted in the practice of critical care medicine in Ontario.

OT donation practices in Ontario are conducted in direct partnership with Trillium Gift of Life Network (TGLN). Expertise, toolkits and on-call donation experts are available for both the set-up and maintenance of donation practices. Hospital based organ and tissue donation committees adapt provincial based policies and procedures from TGLN with hospital specific details, which are typically then reviewed and approved by the Medical Advisory Committee. In the case of OT donation, the following pre-requisites apply:

- Expertise and rigorous unit-based procedural guidelines for Neurological Determination of Death (NDD) and guidelines for Donation after cardio-circulatory Death (DCD);
- Use of guidelines and best practices for the optimization of potentially-transplanted organs;
- Furthermore, it is critical to maintain the high quality EOL care, maintaining the principles of palliative care and the inherent value of life.

13. Clinical Triggers / Referral Indicators for TGLN Referral



Purpose of Tool	The diagram below indicates when TGLN should be contacted if the patient meets clinical triggers/referral indicators.
Intended Use	Directions for using the GIFT mnemonic
Source	http://www.giftoflife.on.ca/resources/pdf/Donation%20Resource%20Manual_Eng11_09_webF.PDF

When do I call?

Call TGLN when a **ventilated** patient meets any of the following referral indicators for high risk of imminent death:



Grave prognosis or Glasgow Coma Scale (GCS) = 3

Injured brain or non-recoverable injury/illness

Family-initiated discussion of donation/withdrawal of life sustaining therapy or treatment (WLS)

Therapy-limited, de-escalation of care, or WLS discussion planned.

In critical care areas (ED/ICU), call TGLN for ALL non-ventilated patients:

- At the time of death (within one hour)
- When the topic of donation is raised by the family

In all other hospital units, call TGLN for non-ventilated patients who are aged 79 and younger:

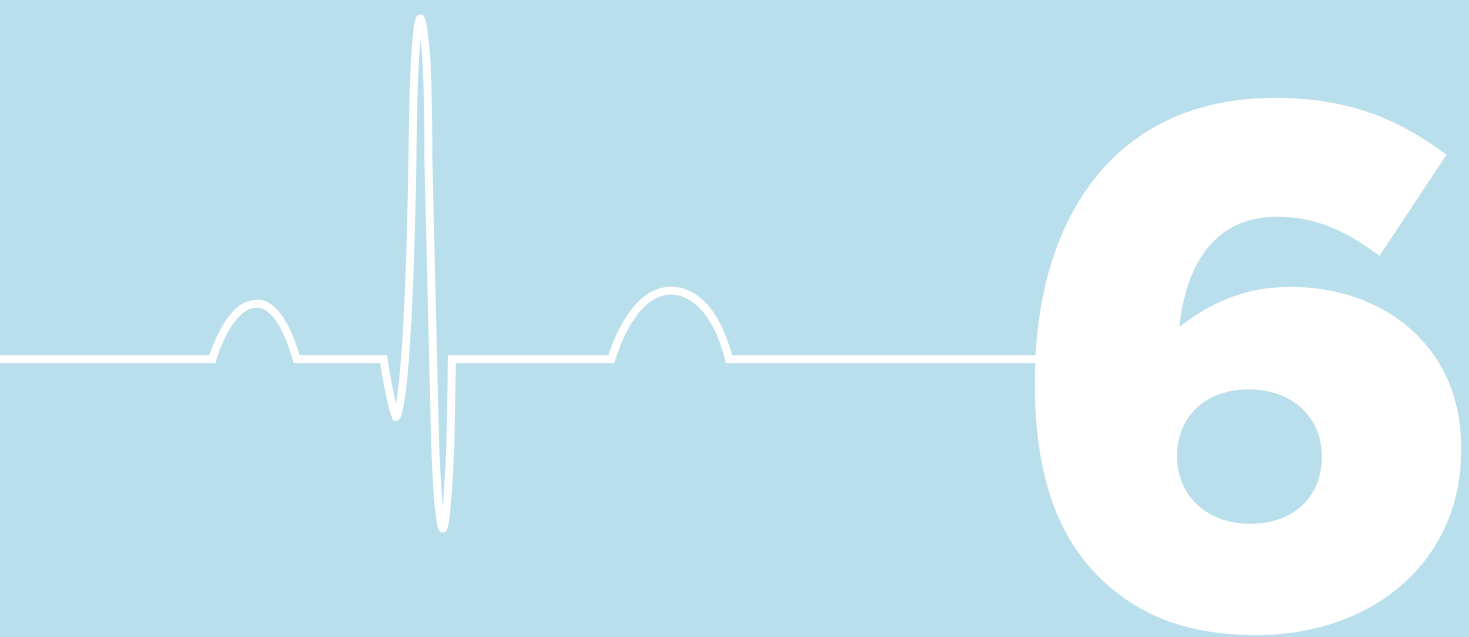
- At the time of death (within one hour)
- When the topic of donation is raised by the family

Note: For all patient referrals a call back to TGLN must occur at time of death, unless otherwise directed by the TGLN coordinator.

Fast Facts

- The act of reporting all patients meeting the referral indicators for imminent death is often called a *Referral* or *Routine Notification*.

Call 24/7 at: 1-877-363-8456 (Toll Free), 416-363-4438 (Toronto)



Conclusion

Conclusion

CCSO is committed to providing ongoing support to health practitioners by ensuring that tools and strategies are available to provide optimal care to patients. As new initiatives and literature becomes available, CCSO will convene stakeholder groups to review and update this toolkit.

It is anticipated that this toolkit has provided clarity with regards to the legal and ethical obligations embedded in the consent process and will encourage health practitioners to employ practices and share innovative approaches to achieve optimal care and improve patient outcomes in critical care services.

SUMMARY OF KEY MESSAGES

Step 1 – Clinical Assessment

- Consent is required from a capable patient prior to treatment and/or procedures, unless emergency circumstances apply where consent cannot be obtained in a practical manner.
- Consent to treatment may be implied or it may be expressed either orally or in writing.
- If the patient is incapable, a substitute decision-maker (SDM) is identified who provides consent to the proposed treatment, which can include, withholding or withdrawal of potentially life-sustaining treatment.
- Ultimately, the patient or their SDM should receive a holistic overview of their medical condition and treatment options compliant with their values, wishes and beliefs.

Step 2 – Values Assessment

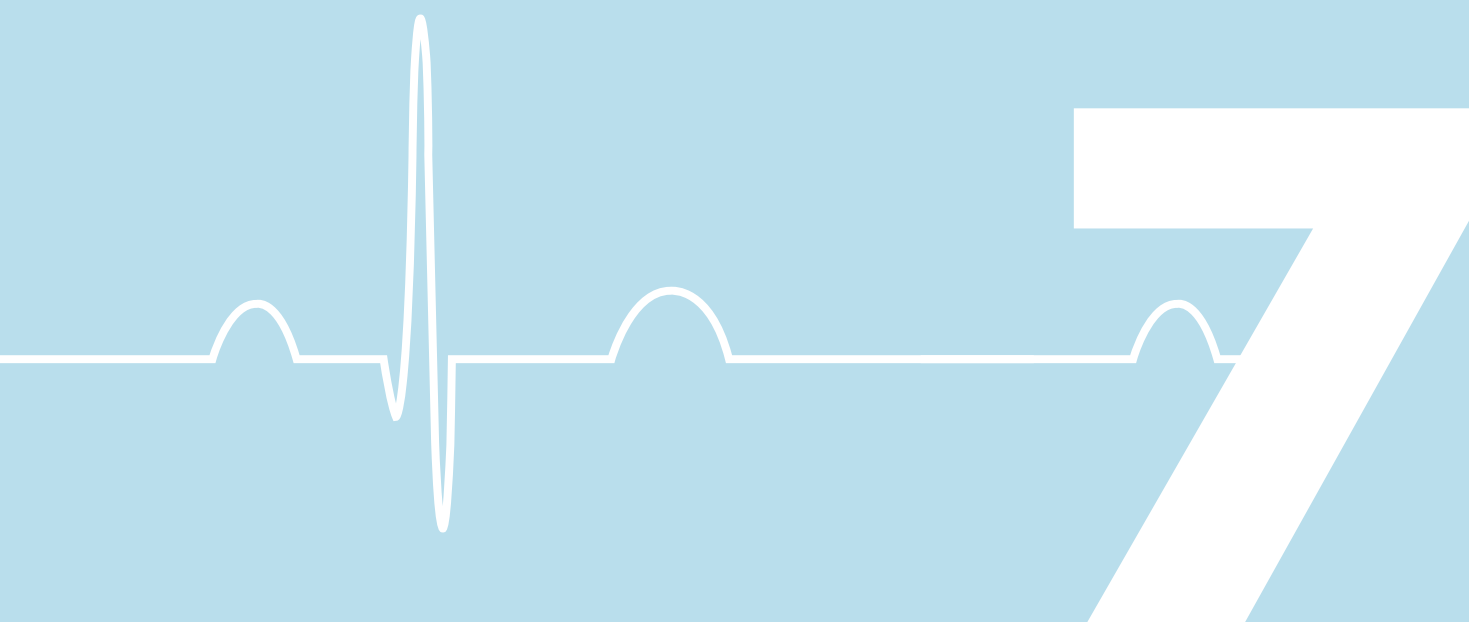
- Treatment plan must be formed with information about the patient's values, wishes and beliefs (sometimes found in advance directive or through speaking to the patient).
- Advanced care planning is a process (not a one-time event) since the patient's health status may change anytime and this may require changes to his/her advanced care plan.
- Advance care plans are directions to SDMs. SDMs need assistance in identifying and working through the sometimes conflicting values relevant to their loved one's medical decisions near end of life.

Step 3&4 – Treatment Options and Selections

- Health practitioners propose treatment plans.
- Health practitioners must be aware of the patient's values, wishes and beliefs and, consider the patient's best interests when proposing withdrawing life-sustaining treatments.
- Early introduction of palliative care and spiritual care support to patients can facilitate end-of-life decision-making. Palliative care offers a viable alternative, does not shorten life and uses comfort medication.
- Physicians have the obligation to secure consent and patients have the legal right to either consent to or refuse treatment. Focused and ongoing conversations therefore are necessary with patients/SDMs in order to minimize conflict.

Step 5 – Consent/No Consent

- Situations where the health practitioner cannot obtain consent from an SDM, which he/she thinks are in the best interest of the patient, can be brought to the Consent & Capacity Board (CCB).
- Before a hearing is triggered, all available approaches to resolve the dispute should be exhausted (e.g. second medical opinions, mediation, communication strategies, bioethics consultations, hospital policies and/or exploring patient transfer).
- It is the right of a capable patient or their SDM to refuse treatment decisions, despite their apparent benefit.



Appendices

Appendix A – Health Care Consent Act (HCCA)

CONSENT TO TREATMENT

No treatment without consent

10. (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,
- (a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or
 - (b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this Act. 1996, c. 2, Sched. A, s. 10 (1).

EMERGENCY TREATMENT

Emergency treatment

Meaning of "emergency"

25. (1) For the purpose of this section and section 27, there is an emergency if the person for whom the treatment is proposed is apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm. 1996, c. 2, Sched. A, s. 25 (1).

Emergency treatment without consent: incapable person

- (2) Despite section 10, a treatment may be administered without consent to a person who is incapable with respect to the treatment, if, in the opinion of the health practitioner proposing the treatment,
- (a) there is an emergency; and
 - (b) the delay required to obtain a consent or refusal on the person's behalf will prolong the suffering that the person is apparently experiencing or will put the person at risk of sustaining serious bodily harm. 1996, c. 2, Sched. A, s. 25 (2).

Emergency treatment without consent: capable person

- (3) Despite section 10, a treatment may be administered without consent to a person who is apparently capable with respect to the treatment, if, in the opinion of the health practitioner proposing the treatment,
- (a) there is an emergency;
 - (b) the communication required in order for the person to give or refuse consent to the treatment cannot take place because of a language barrier or because the person has a disability that prevents the communication from taking place;
 - (c) steps that are reasonable in the circumstances have been taken to find a practical means of enabling the communication to take place, but no such means has been found;
 - (d) the delay required to find a practical means of enabling the communication to take place will prolong the suffering that the person is apparently experiencing or will put the person at risk of sustaining serious bodily harm; and
 - (e) there is no reason to believe that the person does not want the treatment. 1996, c. 2, Sched. A, s. 25 (3)

Source: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

Appendix B – Summary of Findings with the CCB

Since 1996, there have been approximately 30 cases reviewed by the Consent and Capacity Board regarding end-of-life decisions. The outcomes of these cases are summarized in the table below.

Consent and Capacity Board Cases Addressing Best Interests at End of Life

Journal of Critical Care (2010) 25, 171.e1-171.e7	Case	Year	Name	Hospital	Treatment (Plan) Proposed	Board Decision	Appeal
	29	2012	Re (GS)	Ottawa	DNR	Ordered consent	
	28*	2012	Re (FF)	Baycrest	Reasonable expectation; heroic measures... in POA.		
	27**	2012	Re (MN)	Trillium	Withdrawal	Appointed decision maker who agreed with physicians	
	26	2011	Re (AK)	York Central	Withdrawal	Ordered consent	
	25	2011	Re (SR)	Trillium	Palliative	Ordered consent	
	24	2011	Re (MD)	St.Joes, TO	DNR	Dismissed	Upheld CCB Decision
	23	2011	Re (DW)	Halton Health	Withdrawal	Dismissed	
	22	2011	Re (BS)	William Osler	Palliative	Ordered consent	
	21	2011	Re (SS)	Grand River	Withdrawal	Dismissed	
	20	2011	Re (JM)	LHSC	Withdrawal	Ordered consent	Upheld CCB Decision (appealed)
	19	2010	Re (LF)	Belmont House	Maintain G-tube	Dismissed	
	18	2010	Re (DP)	Humber River	Withdrawal	Dismissed (2nd application)	
	17	2010	Re (DP)	Humber River	Withdrawal	Dismissed	
	16	2009	Re (W)	LHSC	Dialysis	Ordered consent	
	15	2009	Re (N)	Grand River	Withdrawal	Ordered consent	
	14	2009	Re (G)	LHSC	Withdrawal	Ordered consent	Upheld CCB Decision
	13	2009	Re (E)	University Health Network	Withdrawal	Ordered consent	Upheld CCB Decision

Journal of Critical Care (2010) 25, 171.e1-171.e7	12	2009	Re (C)	LHSC	Tracheostomy	Ordered consent	
	11	2009	Re (B)	St. Joseph's Health Centre	Withdrawal	Ordered consent	Upheld CCB Decision
	10**	2008	Re (MB)	Rouge Valley	Withdrawal	Appointed decision maker who agreed with physicians	
	9	2008	Re (L)	LHSC	Surgical Graft	Ordered consent	
	8	2007	Re (KMS)	St. Catherines	Withdrawal	Ordered consent	
	7	2007	Re (GA)	North York	DNR/no Vent	Ordered consent	
	6	2007	Re (EJG)	Hamilton	Withdrawal	Ordered consent	Upheld CCB Decision
	5	2007	Re (CD)	North York	Withdrawal	Ordered consent	
	4**	2006	Re (EB)	Scarborough	Feeding Tube	Appointed decision maker who agreed with physicians	
	3	2005	Re (P)	Niagara	DNR	Ordered consent	
	2	2004	Re (IA)	LHSC	Withdrawal	Appointed decision maker who agreed with physicians	
	1	2003	Re (HJ)	University Health Network	Withdrawal	Ordered consent	Overturned CCB Decision
**Form C hearings to determine appropriate decision maker							

Source: *Journal of Critical Care* (2010) 25, 171. e 1 – 171. e7

Link for updated cases reviewed by the Consent & Capacity Board:
<http://consentqi.ca/consent-capacity-board-cases/end-of-life-cases/>

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