

c. "Do you know what the patient would have wanted? What was important to this person?" (share beliefs)

# Checklist

## to Meet Ethical and Legal Obligations to Critically Ill Patients at the End of Life

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### Abstract

Despite improvements in communication, errors in end-of-life care continue to be made. For example, healthcare professionals may take direction from the wrong substitute decision-maker, or from family members when the patient is capable; permit families to propose treatment plans; conflate values and beliefs with prior expressed wishes or fail to inquire about prior expressed wishes. Sometimes healthcare professionals know what prior expressed wishes are but do not respect them; others do not believe they have enough time to have an end-of-life discussion or lack the confidence, willingness and skills to manage one.

As has been shown in initiatives to improve in surgical safety, the use of a checklist presents opportunities to potentially minimize common mistakes and errors. When engaging in end-of-life care, a checklist can help focus on *what* needs to be communicated rather than *how* it needs to be communicated. We propose a checklist to support healthcare professionals in meeting their ethical and legal obligations to patients at the end of life. The checklist should minimize common mistakes, and in situations where irreconcilable conflict is unavoidable, it will ensure that both healthcare teams and family members are informed and prepared.

d. Document what you learn.

- a. "Is there a living will?"
- b. "Do you know your role?"

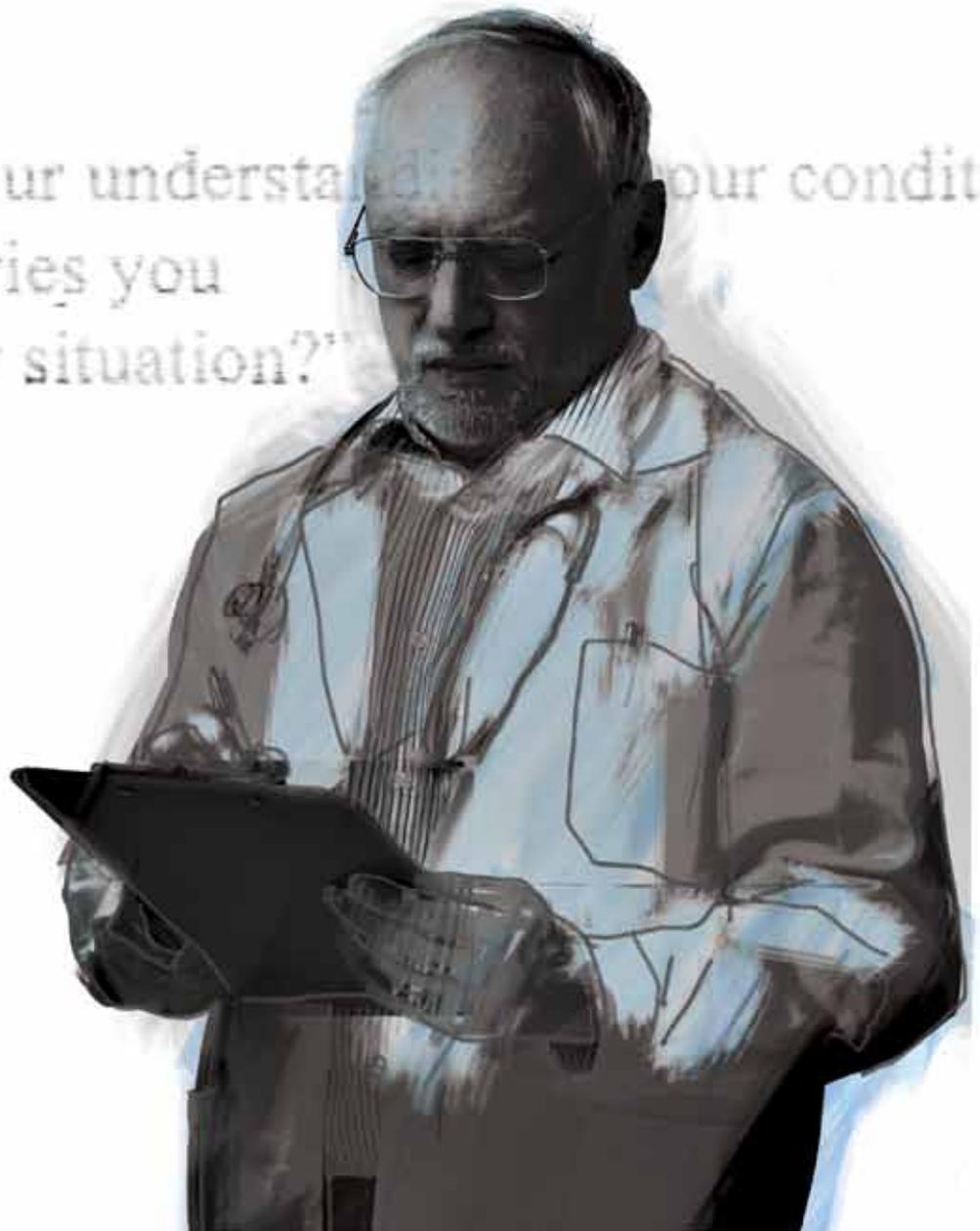
wanted in this situation and  
beliefs or stories)

*What is your understanding of your condition?*

"How do you make decisions in your family?"

"What is your understanding of your condition

"What worries you  
about your situation?"



### Illustrative Case

An 84-year-old patient, Sheila, is transferred to the intensive care unit (ICU) with respiratory failure due to hospital-acquired pneumonia. Sheila has severe functional impairment, two stage-four sacral wounds and difficulty swallowing, with a high risk of aspiration. While discharge home is unlikely, Sheila’s family and her substitute decision-maker (SDM) remain hopeful and believe in her ability to rally. When Sheila suffers a respiratory arrest, a “full code” is run as per the family’s wishes; however, after resuscitation, it is apparent that she has sustained a severe anoxic brain injury. The family continues to insist that “everything be done.” A tracheostomy is performed and, after some time in the ICU, Sheila is transferred to the ward. At this time, the family begins to report that Sheila is communicating with them. They are hopeful that she will soon be back to her old self. One night, she is again discovered in cardiorespiratory arrest due to aspiration of enteral feedings administered through a nasogastric tube. After another code, her physician asks her family, “Do you want us to keep treating her?” The family responds, “It is not for us to decide when she dies; it is up to God to decide. And we cannot lose our grandmother right now – she means too much to us.”

### Background and Introduction

Error in medicine has been defined as “failed processes that are clearly linked to adverse outcomes” (Hofer et al. 2000). “Adverse outcomes” might be anything from longer recovery times to unnecessary suffering and death. However, the concept of medical error does not properly address mistakes that might arise while treating the dying patient. Adverse outcomes at the end of life require more thought because while, traditionally in medicine, death itself would be considered the worst of errors or adverse events, this does not account for the fact that 100% of persons will die. Therefore, there may be better and worse ways to die (the philosophy of palliative care presupposes this fact) (Downie 2004). So error at the end of life must consider adverse outcomes *other* than death. When death is expected for a patient in the ICU or elsewhere, there are several types of error that we do not always consider (Table 1).

**TABLE 1.**  
**Examples of “error” at the end of life**

- Not acting on applicable wishes of patients made when they were capable
- Not identifying who the legal substitute decision-makers (SDMs) are
- Not explaining the consequences of the treatment alternatives, resulting in unrealistic expectations
- Allowing family members or SDMs to “direct” care, resulting in treatments that are not indicated

Repercussions of these errors include moral distress and moral residue for the family and treatment team (Choong et al. 2010; Kuhl 2003; Tulskey 2005); prolonged stays in the ICU; and confusion, misunderstanding and conflict between team members or between healthcare professionals and family members (Heyland et al. 2006; Studdert et al. 2003). These errors, when not identified, can also be the source of team-family conflict (Azoulay et al. 2009; Breen et al. 2001; Choong et al. 2010; Luce 2010a). It has been suggested that conflict regarding the end of life should be addressed by creating policies and statements that guide healthcare professionals’ behaviour (Brett and Jersild 2003; Choong et al. 2010; College of Physicians and Surgeons of Manitoba 2007; College of Physicians and Surgeons of Ontario 2003) or defining notions of futility/inappropriateness (Schneiderman et al. 1990; Sibbald et al. 2007). While formally established professional opinions have provided information about “end-of-life conflict” (Truog et al. 2008), such documents have done little to prevent it (Luce and Alpers 2001). Other authors have suggested that underlying all these errors is poor communication (Breen et al. 2001; Campbell and Guzman 2003; Curtis 2004; Luce 2010b; Studdert et al. 2003), and several mnemonics have been created to trigger important elements to raise in conversations (e.g., ASCEND – anticipate, summarize, [acknowledge] concerns, explore/explain, next steps, document; VALUE – value, acknowledge, listen, understand, evaluate; etc.) (Knops and Lamba 2010). While these tools are useful in considering how one should communicate, they do not address what information is necessary to communicate in order to meet legal and ethical obligations to the patient. Further, if errors lead to conflict, they may actually be the source of communication problems rather than the other way around.

There is uncertainty regarding what constitutes an “end-of-life conversation” (e.g., who should be involved, when it is appropriate and what should be discussed) and also a lack of comprehensive documentation on end-of-life conversation (Ratnapalan et al. 2010). For these reasons, we propose a checklist that will help healthcare professionals to meet their basic ethical and legal obligations to patients at the end of life, and documentation to support these professionals. As has been shown in initiatives to improve surgical safety (Haynes et al. 2009), the use of a checklist presents opportunities to potentially minimize common mistakes and errors. An effective checklist must be patient centred, process oriented and values driven.

### Legal Framework

The checklist draws heavily from Ontario’s Health Care Consent Act (HCCA)(1996) because it is more detailed than the consent laws from other jurisdictions (e.g., it includes notions of withdrawal and withholding in its definitions) and also provides a novel process for resolving conflicts (i.e., the Consent and Capacity Board) that physicians find beneficial

(Chidwick and Sibbald 2011) and that has proven more efficient than traditional court processes (Sibbald and Chidwick 2010). However, the broad ethical and legal principles are the same across Canada, and this checklist can be used in any Canadian province.

**Checklist**

In order to meet one’s ethical and legal obligations and minimize errors when providing end-of-life care, we propose using the checklist outlined in Table 2, some of which is detailed below.

**Ask the Capable Patient about Wishes and Beliefs**

Taking direction from capable patients is required by the ethical and legal principles that underlie the principle of autonomy and the HCCA (1996). Sometimes healthcare professionals turn to capable, caring, informed families for direction on treatment decisions despite the fact that the patients are capable. Ask your patients how they make decisions in their family and how they

would like decisions to be made. In some cases, patients’ or families’ cultural values reflect different models of decision-making (e.g., an elder family member makes all decisions or a group of family members or friends make decisions). Whatever the model of decision-making is, it should be respected (within the law) and documented. Patients are presumed to be capable unless they no longer have the ability to understand the information required to make a decision or to appreciate the consequences of making a decision (HCCA 1996). It is only in this circumstance that we can ethically and legally take direction from SDMs. The HCCA also requires that the practitioner proposing a treatment be responsible for determining the capacity of the patient (HCCA 1996). If patients are deemed incapable, practitioners must document a finding of incapacity (and the reasons for it) and, where appropriate, explain the finding and its consequences to the incapable patients, advise of the right to challenge the decision and assist with that process if the patients indicate a desire to do so.

**TABLE 2.**  
**Checklist for meeting ethical and legal obligations at the end of life**

Step	Dialogue and Documentation
1. Ask the capable patient about wishes and beliefs.	a. “What is your understanding of your condition?” b. “What worries you about your situation?” c. “How do you make decisions in your family?” d. “What is important to you right now when making decisions?” e. If the patient is not capable, document this before proceeding to step 2.
2. Identify the legally correct SDM.	a. See hierarchy of decision-makers (HCCA, Sec. 20; Government of Ontario 1996) b. Document decision-maker(s)
3. Ask questions of the SDM.	a. “Is there a living will?” b. “Do you know your role?” (e.g., to act on prior expressed wishes or best interests) c. “Do you know what the patient would have wanted in this situation and what was important to this person?” (share beliefs or stories) d. Document what you learn.
4. If there is no prior applicable wish, inform the SDM about “best interests.”	“If there are no prior expressed wishes, we then have to consider what is in the best interests of the patient – this means we can propose treatments that will change or improve the condition of the patient for the better, while taking into account this individual’s goals, values and beliefs.”
5. Propose an indicated treatment plan.	a. “We are going to do what will benefit your loved one, and we will continue the treatments that are indicated and in [his/her] best interests.” OR b. “[Patient’s name] is really sick. We will provide treatment that improves or changes [his/her] condition for the better, so that leaves us with the following options: palliative care, comfort care ...” c. “When a treatment is no longer indicated, we will let you know that we are no longer providing it.”
6. If NO consent is obtained, state the following.	a. “It is a challenge when we cannot reach agreement; however, we have a resource that can help us, called the Consent and Capacity Board. It is a neutral third party that will come into the hospital and listen to both sides of the story. The board will then decide what is in the best interests of the patient.” “The patient would be appointed a lawyer, and the physician may have a lawyer as well.. You personally are entitled to have one also (refer to www.ccboard.on.ca).” b. Document that you have explained the role of CCB. Give the family time to ask questions.

CCB = Consent and Capacity Board; HCCA = Health Care Consent Act; SDM = substitute decision-maker.

### Ask the SDM about Prior Expressed Wishes and Values and Beliefs of the Patient

In some end-of-life cases, the healthcare team turns to the first identifiable family member to make decisions. However, it is the responsibility of healthcare professionals to identify the legally correct SDM(s) to obtain consent. Culturally, there are many approaches to familial decision-making. For example, some interpret kinship relations in a way that is not reflective of the HCCA interpretations of kinship. In the HCCA, *brother* or *sister* refers to a genetically related or legally adopted sibling; whereas for some people, *brother* or *sister* may refer to someone who has significant meaning in the patient's life but is not legally related. In situations where there are multiple SDMs, a reasonable effort must be made to reach all of them. The HCCA sets out the hierarchy of SDMs and requires that they be *willing*, *available* and *capable* with respect to the treatment decision for which consent is sought (HCCA 1996). SDMs need to be informed of their obligations in decision-making (HCCA 1996): they must consent or refuse consent first in accordance with applicable wishes expressed by the patient when he or she was capable; if no such wishes exist, then SDMs must consent or refuse consent based on *best interests*, as the legislation defines that phrase. Required considerations of best interests are carefully detailed in section 21 of the HCCA to include the patient's values and beliefs as well as the clinical situation (e.g., is the patient likely to benefit from the proposed treatment?). SDMs *cannot* legally consent or refuse consent based on what they prefer for the patient – although in practice, this often occurs (Sibbald and Chidwick 2010).

Ask SDMs about the patient's prior expressed wishes and values and beliefs. One way to do this is to have SDMs recall a story about the patient (Goold et al. 2000). The patient's values and beliefs should inform how "benefit" is construed (College of Physicians and Surgeons of Ontario 2006).

SDMs cannot propose treatments, although they quite commonly do. Nothing in the law requires a health practitioner to accede to proposals made by SDMs (or even patients, in some cases) for treatments that in the opinion of the practitioner are not indicated or offer no medical benefit. It is important to clearly communicate what is being proposed and in some cases to put limits on the duration of *proposed* treatments. Discussions about all of the above should be documented.

### Form and Propose a Treatment Plan to the Patient or SDM

Treatment plans are defined in the HCCA as being proposed by one or more practitioners to resolve a condition or number of conditions. A plan of treatment may also include the withholding or withdrawal of a treatment. Healthcare professionals meet their ethical and legal obligations when they propose a treatment plan that is medically indicated and that

reflects the patient's previously expressed (when capable) wishes applicable to the circumstances and/or the patient's values and beliefs. There is no ethical or legal obligation to propose a treatment plan that is not medically indicated. However, it may be unclear whether a life-sustaining treatment is indicated or not.

There is a difference between a treatment the family demands but the physicians feel is not indicated, and a treatment the family demands, but the physicians feel is indicated, but not beneficial. Either way, it is not appropriate to take direction from SDMs on what is indicated. Deciding what treatment is indicated is a matter of professional integrity.

Physician must exercise their judgment in determining indicated treatments. The legal interpretation of the standard of care may be useful in this regard. In *Crits v. Sylvester* (1956), the court described *standard of care* as "the degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing." How practitioners decide what is indicated can be done through collaborative approaches (e.g., board rounds, team rounds) that have been found useful in similar circumstances. In Ontario, the College of Physicians and Surgeons also provides guidance in its policy on end-of-life treatments. In particular, it describes the circumstances in which end-of-life treatment should not be offered: "[When] there is almost certainly no chance that the person will benefit from CPR [cardiopulmonary resuscitation] and other life support, either because the underlying illness or disease makes recovery or improvement virtually unprecedented, or because the person will be unable to experience any permanent benefit" (College of Physicians and Surgeons of Ontario 2006). Whatever agreement or disagreement is found among team members should be documented. If no agreement can be reached regarding the determination that a treatment is not indicated (and should therefore not be proposed), then a treatment plan that is determined to be in the best interests of the patient (that may include withholding or withdrawal) should be proposed to the SDM for consent.

Treatment plans may have to change when a patient's condition changes. This information should be shared with SDMs when initiating treatment if it is reasonable, or when the patient's condition requires it. This sharing of potential outcomes is especially important for SDMs who may have unrealistic expectations about treatment plans and who may not appreciate the limits of treatment. Discussions should be documented.

Treatment plans and changes to them require consent, unless these treatments are no longer indicated. To meet the legal obligations of informed consent, the treatment decision must be informed, voluntary and provided by the legal SDM. In end-of-life situations, proposing treatment plans in a positive way is more effective than focusing on what is not indicated (Chidwick and Sibbald 2011). For example, if further aggressive treatment would not benefit the patient, then palliative care should be proposed.

If you believe that an SDM is not providing consent in line with prior expressed wishes or best interests of the patient, then an application can be made to the Consent and Capacity Board. The board process as a means of resolving end-of-life conflicts has been described in detail elsewhere (Chidwick and Sibbald 2011; Choong et al. 2010; Parke and Handelman 2008).

### **No CPR and No Escalation**

No CPR and no escalation orders pose unique challenges in that they are often discussed in advance and refer to treatment that the team is *not* intending to perform. However, a patient's condition is not static, so the challenge for the team is deciding whether CPR is indicated in this context and whether a patient's condition can improve to a point where treatment may be indicated. According to the checklist, if agreement can be reached on this point – that treatment is not indicated – then consent is not needed and the order for “No CPR” does not need to be proposed. If the team members are not sure whether CPR is indicated, they can propose an appropriate plan of treatment and seek consent.

### **Conclusions**

While excellent communication is desirable for any end-of-life conversation, healthcare professionals must first and foremost meet their basic ethical and legal obligations to critically ill patients. The use of a checklist for managing these obligations in end-of-life scenarios offers several benefits (Table 3). The checklist we propose can minimize common mistakes and errors when engaging in end-of-life care by ensuring that care is patient centred, process oriented and values driven. Use of the checklist ensures that the team takes direction from the correct SDM; that the SDM consents in accordance with the legislative standards; that decision-making is patient centred by adhering to prior expressed wishes, beliefs and values of the patient; and that there is respect for the professional integrity of physicians proposing treatment plans. Finally, the checklist can reduce uncertainty regarding what constitutes an end-of-life conversation, and it provides clear steps for managing conversations at the end of life.

**TABLE 3.**

#### **Benefits of using a checklist**

Minimizes common errors at the end of life  
Ensures patient-centred decision-making by respecting wishes and values  
Respects professional integrity and clinical judgment  
Ensures that the team meets ethical and legal obligations to patients  
Clarifies what constitutes an end-of-life conversation

### **Illustrative Case Analysis**

While the team is confident that the patient is not capable of decision-making, this is not documented in the clinical notes. (A team using the checklist would document this finding by dictating a note that the patient does not have the ability to understand the situation and appreciate the consequences of making a decision.) Sheila is also too critically ill to be able to understand the “rights advice” and challenge the finding of incapacity. The team discovers through conversation that the son is recognized as the legal SDM, not the husband, and that this family decision-making model is documented. After asking the family what their understanding of the situation is, the team discovers that the family expects that the patient will be fine in a few weeks because hospital visits “do her good.” Also, a birth in the family is expected, and everyone knows that she wants to see her grandchild. There is no explicit advance directive or living will, but the team does find out from her husband that she has said that when the dementia gets really advanced, “Please no heroics ... let me die.” The team also finds out that the patient is a proud, highly valued member of her community who has enjoyed cooking for others and has never wanted to be a burden to anyone. The team takes some time to explain the role of the SDM, and it turns out that the family had no idea that they have to make decisions according to prior expressed wishes or best interests. They express that it is a great relief to learn that they do not have to carry the burden of the decision of life and death of their mother and wife. Based upon the information about prior wishes and values of the patient and the clinical prognosis, the team proposes a treatment plan based on palliative care to emphasize symptom control. They take some time to propose and go over the plan with the family, who are very concerned. A cousin who is also a senator from California and carries a lot of influence wants to be teleconferenced in to participate in the discussion. The son authorizes this sharing of his mother's personal health information with the cousin. During the meeting, the cousin demands that “everything” be done – he has not seen his aunt for a number of years and says she just “cannot die now.” The team explains respectfully that while sharing the information about the patient with the cousin is OK, he does not have a formal decision-making role in the proposed treatment plan. The team gives the family some time to think about the decision and explains that there is a conflict resolution resource that both the healthcare team and family can access called the Consent and Capacity Board if an agreement cannot be reached or if the family cannot decide whether palliative care respects the patient's wishes, values and beliefs. A day later, the patient's son consents to palliative care. **HQ**

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