



Canadian Geriatrics Society

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FACILITATING EFFECTIVE END-OF-LIFE COMMUNICATION – HELPING PEOPLE DECIDE

Abstract

Given the aging population and the greater number of people with frailty engaging with the health care system, there has been increasing focus on end-of-life communication and decision-making. Advance care planning and goals of care discussions are commonly encountered aspects of end-of-life communication. Good end-of-life communication can improve quality of life and enhance satisfaction with care, but is not consistently done, or done well, by physicians.

This paper reviews definitions of advance care planning and goals of care, in the context of legislation in different provinces. It provides some ideas on facilitating discussions and highlights opportunities to enter into discussions with patients and substitute decision-makers, including the identification of frailty. There are online and other resources that can assist physicians and patients and their families in having successful conversations to guide care.

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Background

Given the aging population and the greater number of people with frailty engaging with the health system, there has been increasing focus on end-of-life (EoL) communication and decision-making.¹ It is a challenging area for professionals and patients, and good EoL communication requires an understanding of provincial legislation and ethics as well as good communication skills. It also needs compassion and sensitivity. In this paper, we discuss advance care planning (ACP) and goals of care discussions, review Canadian legislation on ACP, and consider the ethical aspects of EoL communication and decision-making. We also hope to provide practical ideas for conversations and decisions.

The terminology can be confusing

To guide us, we used the conceptual framework developed by the Canadian Researchers at the End of Life Network (CARENET – see www.thecarenet.ca), which broadly defines *end-of-life communication and decision-making* as a process that includes discussion of death and dying, for example as a potential outcome of treatment or illness progression.² This framework distinguishes three dynamic processes: 1) advance care planning, 2) goals of care designation and consent to treatment, and 3) documentation.

Advance care planning (ACP) is a process of reflection and communication in which a capable person makes and expresses their wishes with respect to future health and/or personal care preferences, and identifies the individual(s) entrusted to ensure those wishes are followed should they become incapable of giving informed consent. The process may also involve conversations with health care providers and significant others. Although the terms may overlap, goals of care discussions are the decisional process around specific, situational treatment options. These discussions involve management of medical issues, such as during a period of hospitalization or acute illness, and are sometimes called a Treatment Plan or Orders in this context. There are similarities between goals of care and ACP; they should be viewed as intertwined entities. ACP does not require a physician to be involved in the development of a plan.

Why is EoL communication important?

Although 95% of Canadians feel it is important, only 30% have had any discussions about medical preferences in case of serious illness and only half of those have recorded ACP/directive.³ Furthermore, only 9% have had EoL discussions with a physician. Even individuals with recognized life-limiting conditions report low rates of EoL discussions. For example, 90% of dialysis patients report having no discussions about prognosis or wishes despite an annual mortality rate of 22%.⁴ There is often poor communication between hospitals, long-term care (also known as nursing homes), primary care and community services about previous and recent discussions/decisions concerning patient preferences and decisions.

Physicians do not do a great job with EoL communication but does it matter? The evidence for ACP is somewhat variable but generally supports ACP as being beneficial for individual patients and families, as well as for health care services utilization outcomes. Limited or delayed EoL discussions are associated with poorer quality of life, greater anxiety and family distress.⁵ Delays can result in prolongation of the dying process, unplanned hospitalizations and patient mistrust of the health care system.⁶ Negative impacts also include physician burnout and higher health care costs.^{7,8} Conversely, proactive EoL conversations can contribute to improved clinical outcomes, better quality of life, improved mood, longer survival,⁹ and reduced costs.^{8,9}

Know the laws where you practice

There is a wide variation in legislation across Canada but all jurisdictions focus on substitute decision-making as the cornerstone of EoL communication. Patients may have undertaken previous ACP discussions in other provinces that may not be applicable to their current location. Family members living in different provinces may also approach the ACP process with different assumptions and expectations. The key legislations related to ACP are summarized in Table 1. Instructional directives are written documents that state what health care decisions are to be made when the person is unable to make decisions. The legislation on these directives is

quite variable across Canada. Instructional health care directives have legal status in Alberta, Manitoba, Newfoundland and Labrador, Nova Scotia, Northwest Territories, Prince Edward Island and Saskatchewan, where physicians are obliged to follow those directives unless there are compelling reasons not to do so, but they are not legally recognized in British Columbia, Yukon, Ontario, Quebec or New Brunswick. Although it is commonly used, the term “living will” has no legal foundation in any Canadian province or territory.

The majority of provinces indicate a clear hierarchy for selection of the proxy decision-maker for people in the absence of formal documentation by the patient. There is, however, interprovincial variation in the terms used to describe who would be the proxy decision-maker. The terms include “Agent” (Alberta, Northwest Territories and New Brunswick); “Proxy” (Prince Edward Island, Manitoba, Saskatchewan and Yukon); “Representative” (British Columbia, Newfoundland and Labrador); “Mandatory” (Quebec); “Substitute decision-maker” (Ontario); and “Guardian” (Nova Scotia). It is important to know who will legally act on behalf of your patient, and to ensure the patient is the primary decision-maker until they are no longer capable or unable to communicate their wishes.

When should it happen and who should do it?

Given the views of Canadians and the evidence of benefits, it seems reasonable to suggest that ACP conversations should be done more frequently and should happen early in the course of any potentially life-limiting situations or serious chronic illness. Likewise, goals of care discussions should happen at time of admission to hospital or worsening of chronic conditions. If patients have an existing ACP, this makes the discussion about the approach taken for the specific circumstances easier. Primary care physicians are well placed to take the lead in initiating or reassessing the need for ACP¹⁰ given their knowledge of the person and their role in continuity of care.¹¹

There are opportunities and situations, which can be used to flag the need for EoL conversations. A change in health status, such as a new and serious diagnosis, recent hospitalization, a decline in function or cognition associated with an increased need for caregiver supports, can be an impetus to ‘speak up’ (see www.advancecareplanning.ca). Changes in a person’s social situation can also precipitate the need for new discussions or a review of old plans; (i.e., “Now that you are living on your own since your wife died, have you given thought to who you would want to make health care decisions for you if you were too sick to do it yourself?”). Discussing perspectives with patients who have dementia is best done early in the course of the illness when the patient is capable.

Many physicians have heard of the so-called ‘surprise question’– “Would you be surprised if this patient died in the next year?”. Although it sounds like a casual sort of question, there is evidence that it does help identify people who are at increased risk of dying.^{12,13} If physicians work with a predominantly older and frailer population, this question should come to mind frequently and can be an impetus to consider your patient’s (and your own) perspectives on treatment goals. Other factors associated with an increased risk of death and an increased need for ACP are shown in Table 2.

Choosing Wisely Canada (CWC [recommendation 2](#)) has several recommendations for patients and physicians that relate to ACP and goals of care discussions. CWC succinctly recommends – *Don’t delay advance care planning conversations*. Although not specifically related to ACP, another recommendation parallel to goals of care discussions is: *Don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment*.¹⁴

Does Advanced Care Planning (ACP) equal consent?

The concept that ACP discussions are not surrogates for consent for treatment is important in hospitals and for care in the community.¹⁵ One example of how this concept can lead to misunderstandings and potentially inappropriate treatment is found in the use of ACP documentation for nursing home residents. If at the time of admission a preference was documented about transfer to acute care in the case of an illness, it would be inappropriate to blindly follow this directive months (or even years) later without a process to seek consent

based on the specifics of the circumstance at hand. For example, if the long term care resident did not wish transfer to hospital but fell and broke their hip, it would be very appropriate to have further conversation about the merits of hospital transfer for symptom control and quality of life rather than relying solely on the documented preference.

Frailty as a cue to need for advance care planning conversations

There is increasing understanding of the physiological and social factors related to frailty (see [Clinical Frailty Scale](#)) but also the impact of frailty on function, vulnerability and life expectancy. There is a clear association between frailty and mortality.¹⁶ Many people with frailty and their family members recognize the presence of symptoms/signs/criteria for frailty but do not necessarily equate them with the likelihood of death in the near future. There is no single tool to diagnose and measure frailty but there are a number that are quick and manageable in hospital and primary care settings. Two commonly used frameworks are the Frailty Phenotype and the Clinical Frailty Scale.^{17,18}

The identification of frailty may help alert professionals and lay people to the need to share perspectives and consider treatment preferences, and to guide specific treatment decisions. Kenneth Rockwood suggests that we view care through the frailty lens, which can give us a common language to engage in conversations with patients and families about the goal of optimal quality of life. Physicians with a good understanding of frailty may use it to advise patients, as well as medical colleagues, on the merits of intensive or aggressive investigations and treatments guided by the likelihood of benefit, life expectancy, impact on function and quality of life.

Goals of care – what is the point of “code status” discussions?

Many of us remember being a clinical clerk sent to “get the code status” at time of hospital admission. This approach, often mandated by hospital policy, is a cross between ACP and goals of care discussion, depending on the circumstances. Many physicians and other health professionals believe these discussions represent a form of ongoing consent for treatment (or consent not to treat). Although these discussions are crucially important to guide care over the course of the specific treatment period, ethically and legally they are not actually valid consent for treatments at other times or settings and except in an emergency situation. Further discussion should occur at each transition in care if there is likely to be a need for cardiac resuscitation or other aggressive interventions.

It may be more fruitful to view hospital “code status” discussions as providing two important functions:

- Guiding the physician or other health professional in an emergency situation, such as a cardiac arrest, during that course of care. If there is no way to get consent from a capable patient or substitute decision-maker in an urgent situation, the documented discussion and treatment preferences should provide information to help make an emergency decision (e.g., initiating CPR, or not).
- Helping staff understand the patient or substitute decision-makers’ perspectives, values and treatment preferences for a range of potential treatments. These discussions are relevant to “prime the pump” by providing information that could be helpful to guide discussions for a treatment decision for a specific illness or circumstance (i.e., true consent for treatment).

Resources

A framework that can help physicians to advise patients with life-limiting illnesses is seen in Table 3. There are articles that focus on providing practical examples of EoL communication to help provide physicians with wording and language that can make difficult conversations a little easier.¹⁹ [ePrognosis \(eprognosis.ucsf.edu\)](http://eprognosis.ucsf.edu) is a website that provides guidance on the prognosis for patients who don’t have a primary terminal diagnosis. It also has video vignettes of simulated discussions.

The Centre for Studies in Aging and Health at Providence Care has developed online learning modules and resources to help health professionals understand and feel more comfortable with these discussions. Although the legislation that provides the framework is from Ontario, the concepts and suggestions are relevant across the country (see www.sagelink.ca).

Speak Up is a national initiative trying to start conversations within families and with health professionals about ACP. They have developed workbooks that can help guide discussions and document preferences. They also have a decision aid to assist with resuscitation decision-making. (see www.advancecareplanning.ca/resource-library)

The Palliative and Therapeutic Harmonization (PATH) approach is an example of integrating ACP into care plans (see "[Palliative and Therapeutic Harmonization: Expanding the Orientation of Geriatric Medicine](#)").

The Ottawa Hospital Research Institute has developed a series of decision aids that can assist with ACP, including a section on EoL care (see [Patient Decision Aids](#)).

In this edition of the CGS CME Journal, Dr. Azad's article on end stage CHF and Dr. Gordon's article on medical assistance in dying represent examples of ACP (albeit in very late stages).

Advanced Care Planning and physician-assisted death

There has been great controversy about the role of advance directives to allow people with progressive illnesses such as dementia to request medical assistance in dying (MAID) in the future, allowing substitute decision-makers to choose MAID if the patient becomes incapable. The legislation, as written at time of writing, does NOT allow for this provision and patients must be capable of making decisions to receive physician-assisted death.

Conclusion

Physicians play a crucial role in stimulating and facilitating conversations that lead to advance care planning. ACP and goals of care discussion (or lack thereof) can have an impact on quality of care for patients and their families. The identification of clinical frailty should be one of several factors to start discussions about treatment preferences and values. ACP documentation provides guidance when a medical decision needs to be made but is not consent for treatment in and of itself.

TABLES:

Table 1. Summary of provincial legislation related to EoL communication

Province or Territory	ACP-related legislation	Term used for Proxy	Proxy selection	Instrumental Directive
Alberta	Personal Directive Act	Agent	“Nearest relative”	Yes
British Columbia	Representation Agreement Act Health Care (Consent) and Care Facility (Admission) Act	Representative		No
Manitoba:	The Health Care Directives Act	Proxy	Hierarchy of Proxy	Yes
New Brunswick:	Power of Attorney for Personal Care (Infirm Persons Act)	Agent		No
Newfoundland and Labrador:	Advance Health Care Directive Act	Representative	Hierarchy of SDM	Yes
Nova Scotia	Authorization (Personal Directives Act, 2010)	Substitute decision-maker	Hierarchy of SDM	Yes
Northwest Territories	Personal Directives Act, 2006	Agent		Yes
Nunavut	Guardianship and Trusteeship Act	Guardian	Hierarchy of nearest relative	No
Ontario	Power of Attorney for Personal Care (HCCA, 1996; Substitute Decisions Act, 1992)	Substitute decision-maker	Hierarchy of SDM	No
Prince Edward Island	Consent to Treatment and Health Care Directives Act	Proxy		Yes
Quebec	Mandate in case of incapacity / Power of Attorney (Civil Code of Quebec; Code of Civil Procedure; Public Curators Act)	Mandatory	“Nearest relative”	No
Saskatchewan	Health Care Directive (The Health Care Directives and Substitute Decision Makers Act)	Proxy	Hierarchy of nearest relative	Yes
Yukon	Advance Directive (Care Consent Act)	Proxy	Hierarchy of proxy	No

Table 2. Clinical factors associated with high likelihood of death in one year²⁰

- **Age > 55 years and 1 or more of the following:**
 - COPD (two of the following: baseline arterial partial pressure of carbon dioxide > 45 mm Hg, cor pulmonale, episode of respiratory failure within the preceding year, forced expiratory volume in 1 s < 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 the following: hepatic coma, Child class C liver disease, Child class B liver disease with gastrointestinal bleeding
 - Cancer (metastatic cancer or stage IV lymphoma)
 - End-stage dementia

- **Any patient ≥ 80 years of age with multiple comorbidities and recent functional decline/cognitive impairment admitted to hospital (Frailty Scale 7–9)**

- **You answer “no” to the following question: “Would I be surprised if this patient died within the next year?”**

Table 3. Four questions to guide goals of care discussions²¹

In his book *Being Mortal*, Atul Gawande cites four questions that clinicians should ask during discussions about goals of care. These perspectives are particularly important in patients with a non-malignant diagnosis, including frailty, since patients and caregivers do not always realize the gravity of their diagnosis.

If the patient can tell the physician the answer to these questions, the physician will be better placed to provide guidance to help them make decisions:

1. Does the patient know their prognosis?
2. What further goals do they have? What would they like to achieve in the time they have left?
3. What are their biggest fears for what lies ahead?
4. What are they willing to suffer or sacrifice for a longer prognosis?

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