


Review Article

Choosing Wisely: Canadian Neurological Society Recommendations for Advance Care Planning

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ABSTRACT: Advance care planning (ACP) is a process to understand and communicate one's wishes, values, and preferences for future medical care. As part of the Choosing Wisely Canada "Time to Talk" initiative, the Canadian Neurological Society (CNS) endorsed the creation of a working group to propose ACP recommendations for patients with neurological illness. A narrative review of primary literature on ACP in neurological and non-neurological illness, medical society guidelines, and publications by patient advocacy groups was conducted. Eight ACP recommendations were deemed relevant and important to Canadian neurology practice and were approved by the CNS Board of Directors. The recommendations are meant to serve as guidance for Canadian neurologists, to stimulate discussion about ACP within the Canadian neurology community, and to encourage neurologists to engage in ACP conversations with their patients.

RÉSUMÉ : Choisir avec soin : recommandations de la Société canadienne de neurologie pour la planification préalable des soins. La planification préalable des soins (PPS) est une démarche qui vise à comprendre et à communiquer les souhaits, les valeurs et les préférences d'une personne concernant ses soins médicaux futurs. Ainsi, dans le cadre de l'initiative « Il est temps de discuter », organisée par Choisir avec soin, la Société canadienne de neurologie (SCN) a appuyé la formation d'un groupe de travail afin qu'il propose des recommandations sur la PPS chez les patients atteints de maladies neurologiques. Pour ce faire, le groupe a procédé à une revue non systématique de la documentation principale sur la PPS dans les maladies neurologiques et non neurologiques, des lignes directrices des sociétés médicales ainsi que des publications par les groupes représentant les intérêts des patients. Huit recommandations sur la PPS ont été jugées pertinentes et importantes pour la pratique en neurologie au Canada, et ont été approuvées par le conseil d'administration de la SCN. Ces recommandations sont offertes à titre indicatif aux neurologues canadiens, et visent à stimuler les discussions sur la PPS dans la communauté de la neurologie au Canada et à inciter les neurologues à parler de la PPS avec leurs patients.

Keywords General neurology; Communication; Neurological practice; Quality of care; Palliative care

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Introduction

Advance care planning (ACP) is a process that supports individuals in "understanding and sharing their personal values, life goals, and preferences regarding future medical care," with the aim of ensuring they "receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness."¹ A survey of nearly 3,000 Canadian adults in 2019 found 80% of respondents felt it was important to discuss ACP with a health care provider, but less than 20% of respondents had an advance care plan in place.² For patients with neurological illness, neurologists can be essential partners in the ACP process.

The importance of ACP has been affirmed in an array of quality metrics and guidelines relevant to neurology.^{3,4} Organizations including the American Academy of Neurology and the Heart

and Stroke Foundation have highlighted the importance of ACP, but guidance on how to integrate ACP into one's neurology practice is limited.

Choosing Wisely Canada is a national organization that aims to improve healthcare quality and delivery by reducing the burden of excessive testing, treatments, and adverse outcomes for patients. Choosing Wisely recently launched "Time to Talk," an initiative focused on ACP, providing the opportunity for medical societies to develop ACP recommendations relevant to their membership and the patient population they serve. The Canadian Neurological Society (CNS) endorsed the development of ACP recommendations. These recommendations are meant to encourage neurologists to engage in ACP conversations with their patients and to stimulate discussion about ACP within the Canadian neurology community.

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1. Don't wait for your patient to bring up ACP, initiate the conversation.
2. For patients with progressive disease that could impact cognition, initiate ACP conversations as early in the disease course as possible.
3. Encourage family and care partner involvement in ACP.
4. Use clear, direct language when discussing prognosis.
5. Use standardized, specific language to document ACP conversations.
6. Don't recommend or initiate aggressive care without establishing prognosis, preferences and goals of care.
7. Revisit advance care plans regularly and whenever there is significant change in a patient's status.
8. Patients who enquire about Medical Assistance in Dying should receive comprehensive information about care options.

ACP, advance care planning.

Figure 1: Canadian Neurological Society Choosing Wisely Recommendations for Advance Care Planning.

Methodology

The Choosing Wisely Canada operating principles and roadmap were used to structure the development of ACP recommendations on behalf of the CNS.⁵ We aimed to develop recommendations which (1) are relevant to Canadian neurologists and trainees across all practice settings and subspecialties, and (2) target common challenges and/or pitfalls to engaging in ACP described in the medical literature.

We reviewed Choosing Wisely statements published by Canadian and American medical societies to identify recommendations of potential relevance to ACP (Appendix 1). We then conducted a search for ACP recommendations published by other medical societies and reviewed publications by patient associations and advocacy groups on ACP (e.g. the Alzheimer Society of Canada and Advance Care Planning Canada, Appendix 2). A narrative review of the medical literature was conducted. The Ovid MEDLINE[®] English language database was searched (2010–2020) using the keywords “advance care planning” AND “neurology” OR “dementia” OR “Parkinson’s disease” OR “stroke” OR “multiple sclerosis” OR “amyotrophic lateral sclerosis.” Article titles and abstracts were reviewed for relevance. We reviewed the references of relevant articles for additional pertinent literature.

Recommendations for ACP were derived by the working group based on the review of the literature and were refined with feedback from the CNS Board of Directors. Eight ACP recommendations were deemed relevant and important to Canadian neurology practice (Figure 1) and were approved by the CNS Board of Directors. A formal consensus-building process such as the Delphi method was not used as the proposed recommendations were unanimously approved by the fourteen members of the Board.

1. Don't wait for your patient to bring up ACP, initiate the conversation

Many patients expect their physicians to start the conversation about ACP.^{6,7} In a study of patients with multiple sclerosis, 64% wanted their physicians to address disease progression and dying.⁸ Additionally, physicians who seemed to avoid raising these issues were rated as less empathetic. In a study of stroke prevention clinic patients, 58% of stroke survivors were interested in having further ACP discussions with their stroke neurologist.⁹

A number of perceived barriers may prevent neurologists from bringing up ACP with their patients. A study of cardiologists and

internists caring for patients with heart failure found common barriers included a lack of time to conduct ACP discussions, fear that bringing up ACP will be perceived negatively or cause patient distress, uncertainty about the role a specialist ought to play in ACP, and personal discomfort with the subject.¹⁰ Evidence demonstrates that ACP conversations are desired and viewed positively by the majority of patients and, indeed, many patients may be waiting for their physicians to start the conversation.^{6–9}

2. For patients with progressive illness that could impact cognition, initiate ACP conversations as early in the disease course as possible

ACP conversations should begin as early as possible in a patient's disease course, particularly for those with illnesses that may impact cognition.^{11,12} A 2014 retrospective nationwide study conducted in Belgium found that only about one in 10 patients with dementia residing in nursing homes had the opportunity to participate in ACP prior to death.¹³ Key clinical events can be used to trigger ACP conversations, including the time of diagnosis, transitions in place of residence (e.g. to assisted living or a nursing home facility), clinical deterioration, or upon patient and family request. Uncertainty about the decision-making capacity of patients with potential cognitive impairment may arise during ACP. Dementia-specific guidelines emphasize that full mental capacity should be assumed and that capacity should be assessed in the moment with respect to particular decisions, given the non-static nature of capacity in the context of cognitive impairment.¹²

3. Encourage family and care partner involvement in ACP

The process of ACP often involves the identification of one or more substitute decision-makers (SDMs) to help guide care in the event a patient is unable to speak for themselves. Involving a patient's family members and loved ones in ACP discussions whenever possible helps ensure SDMs understand the patient's wishes and priorities and what the SDM role entails. Additionally, patient families and care partners may have unique fears and concerns related to their loved one's future care that can be addressed in the ACP process. Involvement in the ACP process may also reduce the stress and uncertainty SDMs feel in the event they have to assume decision-making responsibility.¹⁴

4. Use clear, direct language when discussing prognosis

Straightforward language is best when discussing prognosis with patients and families. Physicians may avoid frank discussion of prognosis due to the uncertainty inherent in prognostication as well as fear of diminishing a patient's hope for a favorable outcome. A shared understanding of prognosis is essential for meaningful ACP discussions, and most patients and families prefer explicit disclosure of prognosis.¹⁵ Further, patients may equate lack of discussion of prognosis as indicating a favorable outlook (i.e. “no news is good news”). In a small study of patients on acute stroke and stroke rehabilitation wards, many patients were unaware of their risk of recurrent stroke and future deterioration, which may contribute to reluctance to engage in ACP.¹⁶ Even when prognosis is explicitly discussed, patients and families may interpret prognostic statements with an optimistic bias.¹⁷ In a survey of patients with newly diagnosed malignant gliomas, the majority reported believing their cancer was curable, and over 40% reported understanding the primary goal of their treatment was cure.¹⁸ Discordance between clinician, patient, and caregiver

understanding of prognosis in malignant glioma is high,¹⁹ which may confound ACP discussions. Helpful guidance on estimating and communicating prognosis in neurologic illness is discussed by Holloway et al.²⁰

5. Use standardized, specific language to document ACP conversations

The value of an advance care plan is contingent on its availability and clarity when and where care decisions are being made. Documentation of ACP is frequently unavailable at the point-of-care.^{21,22} Ambiguous or unavailable documentation decreases the likelihood a patients' wishes can be honored. In Alberta, the "Goals of Care Designation" is a standardized format to describe and communicate the general focus of a patient's care, divided into "resuscitation", "medical", and "comfort" goals.²³ Similar tools are used in Québec (i.e. "Levels of Care and Cardiopulmonary Resuscitation")²⁴ and by regional health authorities in British Columbia (i.e. "Medical Order for Scope of Treatment"). A study across three Québec hospitals found a high rate of patient and family engagement in establishing Level of Care designations.²⁵ In 98.7% of cases, care was consistent with the patient's Level designation at the time of death.²⁵ The shared language provided by such standardized designations may allow for clear communication between healthcare providers; however, designations should be accompanied by a description of the specific goals and values that inform the patient's advance care wishes. Further efforts to improve the accessibility of ACP documentation are required: not all Canadian provinces and territories have standardized tools for documenting ACP, and even in a jurisdiction with a shared vocabulary and a shared electronic medical record, goals of care designations may be unavailable at the point-of-care.

6. Don't recommend or initiate aggressive care without establishing prognosis, preferences, and goals of care

Choosing Wisely recommendations put forth by the Canadian Society of Internal Medicine and the Canadian Critical Care Society highlight the importance of establishing a patient's prognosis, preferences, and goals prior to escalating care.^{26,27} As many as one in three patients receive non-beneficial treatments in the last six months of life, including resuscitation and intensive care for patients with advanced, incurable illnesses.²⁸ Aggressive care for those with advanced disease is associated with decreased quality of life and care satisfaction, in addition to increased healthcare costs. We recommend avoiding the presentation of aggressive care as the default pathway without discussing alternatives, including comfort-focused care, and exploring the patient's wishes and priorities.

7. Revisit advance care plans regularly and whenever there is significant change in a patient's status

ACP is a dynamic, ongoing conversation between patients, their loved ones, and their healthcare providers. Conversations should be revisited as the patient's priorities, goals, and health evolve. Patient awareness that ACP conversations can be revisited may also reduce anxiety related to advance decision-making. As discussed in (2), a variety of clinical events and transitions, such as transitions in care location, can serve as triggers for initiating and revisiting ACP discussions.

8. Patients who enquire about Medical Assistance in Dying should receive comprehensive information about care options

Since 2016, federal legislation has allowed eligible Canadian adults to request Medical Assistance in Dying (MAiD).²⁹ We recommend that patients who enquire about MAiD be provided with comprehensive information about MAiD eligibility, the MAiD process, and relevant alternatives. Provincial and territorial regulatory bodies outline the precise requirements for addressing an enquiry about MAiD, and we recommend neurologists familiarize themselves with their licensing body's guidance.

Limitations

These ACP recommendations were developed following a focused, narrative review of the literature. A formal system for evaluating the quality of evidence for each recommendation was not applied. The recommendations were developed by a small working group (EM, PC) that does not encompass the breadth of Canadian neurologists who may be involved in ACP. These recommendations were unanimously endorsed by the CNS Board of Directors. The scope of these recommendations is targeted to an individual neurologist's practice and does not address other important ACP issues, such as physician remuneration for time spent on ACP conversations and standardization of ACP documentation across jurisdictions.

Conclusions

ACP is central to the provision of patient-centered neurological care and is relevant to neurologists in all practice settings, from outpatient community practice to the neurocritical care unit. The lived experience and media coverage of the COVID-19 pandemic have increased public awareness of the value of ACP. Neurologists are often uniquely positioned to partner with their patients in ACP conversations and can play a key role in ensuring patients' goals and values are understood and honored.

These recommendations are being put forward by the CNS in order to advocate for the role of neurologists in their ACP process, to encourage Canadian neurologists to engage in ACP with their patients, and to stimulate discussion about ACP within the Canadian neurology community. Ongoing advocacy on the importance of ACP in neurological care is required, and further dialogue with patients, families and care partners, neurologists, and other health professionals will be critical to meeting the future ACP needs of our patients.

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The 2021–2022 Board of Directors of the Canadian Neurological Society endorsed these recommendations. Board members: S Peters (President), A Henri-Bhargava (Vice President), A Schabas (Secretary-Treasurer), J Burton (Past President), B Buck (Representative from Alberta), I Poliakov (Representative from Saskatchewan), J Marriott (Representative from Manitoba), A Jahangirvand (Representative from Ontario), A Richard (Representative from Quebec), L Magnusson (Representative from Newfoundland), S Arseneault (Residents' Representative), and H Thornton (Junior Residents' Representative).

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