

CNA's Key Messages on **COVID-19 and Palliative Care**



KEY MESSAGES

- Given the nearly 10,000 deaths of people in Canada due to the first wave of COVID-19, in addition to the 265,000 people in Canada who will die during 2020, it is imperative that palliative care and a palliative approach to care continue to be cornerstones of nursing care.^{1,2}
- The Canadian Nurses Association (CNA), the Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Hospice Palliative Care Nurses Group (CHPC-NG) believe that high-quality, adequately staffed and accessible specialized palliative care delivered by regulated nurses as part of an interdisciplinary team should be available for all people during the pandemic. A palliative approach to care must also be supported throughout the pandemic as this approach "help[s] people live well until death, across the lifespan, in all practice settings".3
- During the pandemic, palliative care provided by nurses is essential for addressing pain and symptom management; advance care planning and goals of care discussions; ethical dilemmas; anticipatory and complicated grief experienced by family members and caregivers; and complex care needs for highrisk patients, specifically the elderly, people with underlying medical conditions and the immunocompromised.⁴
- High-quality palliative care provided to patients without COVID-19 must not fall by

- the wayside during the pandemic. The government must ensure that appropriate levels of care are provided in ways that limit their risk of exposure to COVID-19.⁵
- Visitor restrictions in palliative and endof-life situations should be based on a case-by-case risk assessment. Policies should account for the serious harms that can result from the absence of family at the bedside and must therefore not follow a "one-size-fits-all" model.
- Imposed isolation for palliative patients who have either been exposed to or tested positive for COVID-19 should be limited to the minimum amount of time necessary to mitigate infection risks. This recommendation applies to settings in which this infection control strategy is tenable.
- CNA supports compassionate visitation protocols during the pandemic that would allow those who are nearing death to visit with their loved ones while following safety measures such as the use of personal protective equipment (PPE), as outlined by the Public Health Agency of Canada.⁶
 Visitation is an ethical necessity for patient safety as it allows for representation and advocacy.⁷ These visitations should take place prior to the last 48 hours of life, while the patient is still lucid and able to communicate.

KEY MESSAGES CONTINUED

- Equity must be maintained by paying greater attention to patients who are underserved including the homeless, incarcerated persons, Indigenous Peoples and rural populations as systemic inequities are aggravated during times of strain on the health-care system.⁸ Additionally, aggressive end-of-life care interventions and death in intensive care units have been associated with racialized and immigrant communities in Canada, highlighting the need for further research in this area to support equitable access to and delivery of palliative and end-of-life care.^{9 10}
- Pandemic-related moral distress, secondary traumatic stress (a stress response that occurs due to knowing or helping a person or persons experiencing trauma) and grief are significant issues facing health-care workers at this time.¹¹
- It is critical that compassionate advance care planning and goals of care conversations are held as early as possible with all patients, their families, substitute decision-makers and health-care workers, ideally prior to the patient developing critical illness, and on an ongoing basis thereafter.^{12, 13, 14}



BACKGROUND

- Palliative care: "an approach that improves the quality of life of persons and their families facing the problem
 associated with life-limiting illness, through the prevention and relief of suffering by means of early identification
 and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".¹⁵
- Palliative approach to care: "a philosophy and set of principles that [apply] to all people living with and dying from a life-limiting illness". 16 It "integrates the philosophies and principles of palliative care into primary care, long term care and all mainstream health services". 17

Palliative care focuses not only on end-of-life care but also, more generally, on personhood, quality of life and alleviation of suffering, irrespective of whether or not someone is imminently dying. ¹⁸ Thus, the risk of inadequate palliative care not only affects those who may die from COVID-19 but also those whose current palliative care plan is altered by the pandemic. ¹⁹

Palliative care is threatened by the pandemic. As a result of visitor restriction policies, patients and their families are choosing not to access palliative care, such as admission to residential hospice, even if they do not have the support they need in their current location. Furthermore, the fundamental notion of a "good death," defined by each patient for themselves and which often includes family at the bedside, is severely threatened due to visitor restrictions. Challenges in relation to medical assistance in dying (MAID) are also concerns at this time. When considered to be a non-urgent medical service, in some hospitals, access to MAID may be restricted. ²⁰ Resource limitations and physical distancing may create difficulties in compliance with legal requirements, such as the need for two independent witnesses to sign a request for MAID. ²¹ The provision of MAID in some circumstances may also be delayed. ²²

Suggestions from a literature analysis performed by the Canadian Institute for Health Information prior to the pandemic indicate that, globally, between 62 per cent and 89 per cent of patients who die could benefit from palliative



care.²³ It is therefore critical that during this time palliative care is maintained for those without COVID-19 as well. To ensure continued provision of this care, CNA believes that the government should support the hiring for the appropriate staff mix and staffing levels in all sectors, with attention given to long-term care (LTC) as these issues are long-standing vulnerabilities of this sector.²⁴ The federal government has developed a <u>Framework on Palliative Care</u> that is already underway and can be used to further support a response to COVID-19 within the palliative care sector.²⁵

ADVANCE CARE PLANNING AND GOALS OF CARE

- Advance care planning: a lifelong process within which patients explore their values and wishes for care, have conversations with family members and friends regarding their future health-care wishes and choose a substitute decision-maker.²⁶
- Goals of care: conversations that aim to identify patients' values and wishes for care in relation to their current clinical situation.²⁷ These discussions are especially important at this time due to the risk of rapid deterioration of patients with COVID-19 and can result in the establishment of decisions regarding medical treatment and symptom control that align with what is of greatest importance to patients and families.²⁸

Having patients and their loved ones partake in advance care planning and goals of care conversations proactively is of the utmost importance to avoid providing patients with unwanted, life-sustaining treatments. Such treatments are especially problematic during times of added stress on the health-care system. ²⁹ Direction found in these conversations can help diminish the psychological burden for patients, families and health-care providers, as well as financial stress on the health-care system, particularly during this time.

There are numerous barriers to these discussions in the current climate, such as issues of trust (related to fears of rationing health-care resources, which is particularly relevant for some Black and minority ethnic groups, along with other communities who experience discrimination, such as LGBTQIA+ groups); a lack of time among staff to devote to patients; a lack of appropriate templates, tools, and systems given the context of the pandemic; and concerns around communicating with families given physical distancing restrictions.³⁰ The importance of these early conversations is heightened even more in light of visitor restriction policies resulting from the COVID-19 pandemic.

Please refer to the *Resources* section for further information regarding advance care planning and goals of care conversations to support patients with and without COVID-19.



The experiences of death and dying during the COVID-19 pandemic can cause emotional difficulties for families and health-care workers alike. Due to physical distancing restrictions, many goodbyes are not able to take place in person, and health-care workers must help patients connect with their loved ones during their final moments



through phone conversations or videoconferencing.³¹ Health-care workers must also inform families of deaths using these forms of communication.³² Visitation restrictions cause distress for the dying person and their loved ones as the opportunity to hold hands, say goodbye, make amends or have a final meaningful conversation becomes limited.³³ Physical distancing restrictions negatively impact mourning customs and rituals as they make it more difficult for people to come together to grieve.³⁴ Additionally, due to physical distancing precautions, many resources, such as respite and day homes, have been halted, leading to an increased workload for athome caregivers.

Anticipatory grief and complicated grief after death due to visitor restrictions and other pandemic-related challenges are possible outcomes for family members and caregivers during this time.³⁵ Nurses should provide high-quality communication to patients and their families, including recognizing, responding to and validating emotional responses, along with helping in the preparation for a possible death.³⁶ This form of communication is a strategy for addressing anticipatory grief and will in turn enhance outcomes for families during the bereavement period.³⁷ Nurses can also connect patients and families to telehealth resources, such as those that provide support for planning and grief following bereavement.³⁸

Further complications that health-care workers could experience due to the COVID-19 pandemic include pandemic-related moral distress, secondary traumatic stress and general grief.³⁹ Nurses and other health-care workers may also grieve their inability to provide care to patients in the form that they wish.⁴⁰



Despite the strain on the medical system at this time, it is imperative that palliative care patients *without* COVID-19 continue to have access to high-quality care. ⁴¹ This is important as palliative care is a human right, and without it there may be exacerbation of illness and suffering; moreover, the health-care system could become further overwhelmed. ^{42, 43} For palliative patients who may have a pre-existing illness and/or be at an advanced age, contracting COVID-19 can be fatal. ⁴⁴ Thus, care should be provided that minimizes potential exposure to the virus.

Transferring patients with life-limiting illness to inpatient care will no longer be feasible if the health-care system is overrun with caring for patients with COVID-19. Within this circumstance, and to help diminish the exposure of vulnerable palliative populations to COVID-19, the establishment of remote palliative and home-based care is critical. ⁴⁵ Primary care providers should partner with palliative care experts and home care agencies to monitor their patients and deliver continuous symptom management support. ⁴⁶ Complications associated with this transition include the possibility of home care staff becoming overwhelmed with a heightened workload. Extensive education and support for home-based caregivers will also be needed. ⁴⁷

The impact of physical distancing at this time for palliative care patients without COVID-19 must also be considered. Despite not having COVID-19, many patients may continue to be isolated from loved ones due to hospital protocols, travel restrictions and physical distancing practices.⁴⁸





- Actions that can be taken to relieve the impact of the pandemic on the palliative care system include ensuring the following⁴⁹:
 - ► That there are sufficient comfort medications, equipment to deliver medications and PPE available, especially within LTC and community settings
 - ► That regulations that limit the availability and prescription of injectable morphine and hydromorphone are suspended
 - That health-care workers are educated regarding palliative care needs and that through regional pandemic planning there is engagement of staff with palliative care experience to ensure specialized palliative care providers are not overwhelmed during a surge
 - ► That space is optimized through the use of hospice beds, particularly for non-COVID-19 patients, and that palliative care units for patients with COVID-19 are established
 - That equity is maintained and focus is paid by health-care providers and government to those who are underserved, including the homeless, incarcerated persons, Indigenous Peoples and rural populations as systemic inequities are aggravated during times of strain on the health-care system
- Rural access to palliative and end-of-life care must be maintained throughout the pandemic as these
 populations may experience even more resource and service access challenges.
- With the absence of visitors and various interdisciplinary members due to physical distancing restrictions
 in some facilities, nurses now have many extra responsibilities. This surge in workload is overwhelming,
 increases their risk of distress and diminishes the amount of time they are able to spend with each patient.
 These changes have not been accounted for in human resource allocation. The expectations of nurses at
 this time must be assessed, and nurses must be better supported within their roles.
- Nurses should ensure that communication is maintained for families and patients who are unable to see one
 another in person due to infection control precautions.⁵⁰ Health-care facilities should offer smartphones,
 tablets or laptops to patients and provide free internet connection throughout the pandemic.⁵¹ Patients who
 are unable to use these communication measures due to their condition should be prioritized for receiving
 support from social workers and spiritual health professionals.⁵²
- With regard to bereavement, it is crucial that nurses care for each other and themselves at this time so
 that they can continue to provide care to patients.^{53, 54} Regular virtual support meetings are recommended
 for staff to come together and reflect on their own feelings during the pandemic and should be specific to
 providing end-of-life care.⁵⁵ Furthermore, bereavement and grief support services should be accessible for
 those who lose a family member, loved one or colleague during the pandemic.⁵⁶
- In a circumstance of limited resources and the possibility of exposure of patients to COVID-19, palliative
 patients with and without COVID-19 can be prioritized. This includes identifying patients who will most
 likely require direct, in-person care regardless of setting, those who can be managed in their present setting
 by means of direct visits or virtual care options, and those who can follow their current care plan and have
 routine follow-up visits postponed.⁵⁷



- Institutional administrators have a responsibility to consistently communicate and work with nurses to
 ensure that palliative care is provided effectively and efficiently throughout the pandemic. Nurses have
 a role in advocating for and taking leadership in institutional policies, and it is critical that administrators
 are receptive to their input.
- Patients with COVID-19 triaged not to receive, or who choose not to receive, intensive care or ventilator support may continue to require relief of suffering, specifically breathlessness, which can be achieved through the use of opioids, anxiolytics and non-pharmacological strategies.^{58, 59} Care providers should ensure that opioid institutional standards, along with opioids, are available; that opioids are prescribed using evidence-based treatment protocols; and that patients are diligently observed to prevent inadvertent negative health effects.⁶⁰



COVID-19-SPECIFIC RESOURCES

Pallium Canada: COVID-19 Palliative Care Modules

(free online learning modules for health-care workers regarding palliative care during the pandemic)

Canadian Virtual Hospice

Speak Up Canada

Speak Up Ontario

How to Talk to Your Loved Ones & Healthcare Team about Your Wishes & Goals If You Become Sick with COVID-19 (New Coronavirus)

Canadian Nurses Association: Nurses' Ethical Considerations During a Pandemic

Fraser Health: Serious Illness Conversation Guide: A Conversation Tool for Clinicians, Adaptation for COVID-19

NON-COVID-19-SPECIFIC RESOURCES

Speak Up Canada: Advance Care Planning in Canada: A Pan-Canadian Framework (2020)

Canadian Hospice Palliative Care Association

Canadian Hospice Palliative Care Nurses Group

Health Canada: Framework on Palliative Care in Canada

Speak Up Canada: Goals of Care Conversation Guides for Patients without COVID-19

Speak Up Canada: Resources and Tools (includes links to provincial and territorial resources)

My ICU Guide (information and medical decision-making support for those who have a loved one in the intensive care unit)

Plan Well Guide (planning tools for yourself or a loved one in the event of serious illness)



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