

## **Improving End-of-Life Care for People with Dementia in LTC Homes During the COVID-19 Pandemic**

### **BACKGROUND**

The devastating impact of the COVID-19 pandemic has resulted in a significant increase in the number of deaths in long term care homes (LTCH), with estimates as high as 64% (1). Prior to the pandemic, in Canada, the annual mortality rates of residents in LTC range from 27% to 52.3% (2–4). Average length of stay is decreasing, especially for residents with higher levels of cognitive impairment (13 months in 2015) (5) as residents move to LTCHs closer to the end of life, with more complex care needs than ever before (6,7)

People with dementia living in LTCHs represent one of the most frail and marginalized populations in Canada. With some exceptions, many LTCHs have not implemented a palliative approach (8) and the LTCH workforce is generally ill prepared to provide this approach. Moreover, there has been a lack of attention to advance care planning (ACP) for people with dementia (9,10). As a result, there has been excessive reliance on invasive medical care at EOL, unnecessary hospital transfers, and many people are denied opportunities to participate in their own end-of-life planning, especially earlier in the illness when they still have capacity to do so (9–11). These issues have been amplified during the COVID-19 pandemic. Families are being required to make important decisions without preparatory engagement or face-to-face discussions, and health care providers in LTCHs are having to initiate ACP and end-of-life discussions without essential competencies.

Moreover, the surge of COVID-19 cases in LTCHs and rationing of healthcare resources during the current pandemic (12,13) have amplified the pre-existing need for improvements in palliative and EOL care in LTCH settings.

This statement provides key recommendations to improve the care of people with dementia living in LTCHs during the COVID-19 pandemic. A multipronged coordinated approach is needed, including institutional policies to facilitate palliative and EOL care, improved communication, educating residents and families/friends about ACP, preparing and educating the workforce in all aspects of palliative and EOL care, and providing resources and tools to support improvements. Recommendations are listed in Table 1. Details about the recommendations are then provided.

**Table 1: Recommendations**

<b>1</b>	Long term care homes should implement a palliative approach to dementia care
<b>2</b>	People with dementia should be engaged in advance care planning early
<b>3</b>	Family members and significant others should be prepared and supported for the end-of-life
<b>4</b>	End-of-life symptoms should be managed effectively
<b>5</b>	After death care should be provided consistently with local public health guidelines and

	evidence about SARS-CoV-2 transmission.
<b>6</b>	Grief and bereavement support should be provided to family members of deceased residents, LTC home staff, and surviving LTC home residents, including residents with dementia.

### **1. LTC homes should implement a palliative approach to dementia care**

The Quality End of Life Care Coalition of Canada endorsed a national framework for a palliative approach to care of persons with chronic, progressive, life-limiting illness, including dementia. This includes initiating a palliative care approach early in the illness trajectory alongside chronic disease management, with a seamless transition to appropriate end-of-life planning and care (14,15).

The term “*palliative care approach*” was first coined in Australia to refer to non-specialist palliative care of older persons in residential care homes. This approach “aims to enhance an older person’s quality of life by promoting the early identification, assessment, and treatment of pain as well as other physical, psychological, social, and spiritual needs to help minimize suffering, while also acknowledging families’ needs” (Phillips et al., 2009, p. 396). It requires that all health care providers who care for patients with serious illnesses be able to identify those with palliative needs throughout the disease trajectory, not just at the end of life; initiate essential conversations; and activate measures to optimize quality of life. Specialist-level palliative clinicians and teams can provide clinical and educational support; as well as clinical supervision for those with very complex needs.

Key elements of a palliative approach that should guide care for people with dementia are described in the other recommendations in this position statement. Fundamentally, this approach requires holistic care that incorporates the psychosocial and spiritual domains of care alongside the physical domain, continuing in advanced stages of dementia. For example, it is crucial to recognize residents’ spiritual care needs through providing opportunities to engage in religious rituals and other activities that meet spiritual needs (17) such as audio/video recitation of religious material or playing music that the person enjoys. Given the visiting restrictions imposed by the pandemic, these activities may also be delivered via creative virtual means involving family/friends facilitated by allied health professionals such as social workers and pastoral care providers.

To implement a palliative approach in dementia care in LTCH, we recommend three overarching strategies:

- a) adoption of the palliative approach in the whole facility
- b) education and training of the whole workforce on a palliative approach to care, and
- c) adoption of tools and policies that enhance care and that support staff to use what they know and learn about a palliative approach and make it part of everyday care (18,19).

Integrating a palliative approach starts with leadership embracing and intentionally supporting it, ensuring the right conditions are put in place for its adoption. There are several tools that can help leadership in the process.<sup>1</sup>

Implementing a palliative approach often requires support from palliative experts outside the LTCH to build capacity within the LTCH. Unfortunately, the COVID-19 pandemic has halted many capacity building activities, as infection control initiatives have taken precedence. This has limited, if not eliminated, support from the wider community for LTCHs to implement a palliative approach to care at a time when it needed more than ever before. We strongly recommend that these activities are a priority and that palliative consultants and specialists should be easily accessible.

Education should be provided to all staff, including personal support workers/care aides, and depending on the staffing model in the LTCH, to contract or consultant health care providers (e.g., rehab professionals, physicians). There are already some promising Canadian-made, ready to deliver education programs. We recommend adopting one of the high-quality education programs that have been favourable received by LTCHs.<sup>2</sup> In addition to formal educational programs, other informal strategies, based on the Strengthening a Palliative Approach in Long Term Care Model (SPA-LTC) (20,21), are recommended. Led by palliative nurse consultants or nurse practitioners, Comfort Care Rounds (CCRs) provide LTCH-wide case-based discussions about deceased residents or those who are dying (Wickson-Griffiths et al., 2015). They should occur at least bimonthly and are mainly focused on providing ‘in-the-moment’ education, reflecting on resident cases, and providing peer support for staff and volunteers. CCRs are even more important now, during the pandemic, to help staff through the number of deaths, particularly the ‘bad deaths’ for those with dementia who are dying alone, which is completely antithetical to their beliefs and training (22).

A palliative approach is important throughout the dementia disease trajectory. A relatively new intervention, called *Namaste Care*, addresses social inclusion and quality of life for people with dementia by engaging them in meaningful and therapeutic activities throughout the later stages of the disease trajectory (23). *Namaste Care* is focused on encouraging meaningful interaction for all participants. Emerging evidence supports this intervention, with improved pain and quality of life, improved family carer outcomes, and reductions in antipsychotic and hypnotic use, and behavioural symptoms (24,25).

## **2. People with dementia should be engaged in advance care planning early**

The pandemic has brought the critical need for advance care planning (ACP) to the forefront. ACP is a “process that supports adults to understand and share their personal values, life goals, and preferences regarding future medical care to help ensure that people receive care that is consistent with their values, goals and preferences during serious illness” (Sudore et al., 2017, p. 821). In the LTCH context, ACP aims to activate critical communication early with residents and families, so that decisions about end-of-life care can be made (27). When ACP does not occur for residents with dementia, family and care providers are not adequately prepared to make decisions at end-of-life. They experience added stress and burden with decisions being made in

‘crisis mode’. This has become even more difficult during the pandemic, given the visiting restrictions for families which have limited their ability to engage in ACP discussions.

Accommodating the challenges imposed by the pandemic, so that residents participate in ACP activities should be a priority given the evidence of positive health outcomes associated with ACP including congruence between older adults’ wishes and EOL care provided; lower rates of unnecessary hospitalization at EOL; reduced stress, depression and anxiety amongst families; and improvements in feelings of autonomy, control and care satisfaction for all parties across the living-dying trajectory(28–36). Telehealth or online modes of participating in ACP during the pandemic are recommended.

To be prepared, people with dementia should be engaged in discussions (that should involve their family members/significant others) to:

1. Choose a substitute decision maker (SDM);
  2. Share with their SDM about their values, wishes and what is important to them; and
  3. Share with their SDM what would matter most to them should they become seriously ill.
- (37)

We recommend using resources for residents, care partners, and clinicians, that support holding ACP conversations in early stages of dementia<sup>iii</sup> and in LTCHs experiencing COVID-19 outbreaks<sup>v</sup>.

### **3. Family members and significant others should be prepared and supported for the end-of-life**

Family members of people dying with dementia are vulnerable to stress, anxiety, social isolation, and decreased well-being (38–43), which has been exacerbated during the COVID-19 pandemic. Advanced dementia is a critical time for family involvement, given that involvement at this time may have an impact on the dying experience of the person with dementia and on the carer’s bereavement and post-bereavement experience (44–46). Providing opportunities to develop and maintain meaningful relationships with a person with dementia during the pandemic is critical to minimize carer burden, stress, conflict, and loss.

To prepare families for end-of-life decision making, it is critical that they engage in ACP discussions with residents who have dementia early when they still have capacity, so that when dementia has progressed, they are well informed and prepared to make decisions about goals of care on the residents’ behalf. To help prepare families, their questions and informational needs should be met either through virtual conversations, online support tools, or written materials (47).

During the 2002-2004 SARS epidemic, staff had to be creative to support families to keep them informed and involved (48,49). Given the growing demand for integration of a palliative approach to care within LTC due to the pandemic and COVID-19 outbreaks, and the increased awareness of service inadequacies due to visiting restrictions, virtual technologies offer a promising way to engage families and prepare them for decision-making when residents are nearing end-of-life and face-to-face discussions are not possible. At the very end of life, families

need to know on what to expect, including the signs of imminent death. They should be prepared for and included in discussion about withdrawing or stopping treatments that are not helpful.

Sitting vigil while a person is dying is a deeply ingrained norm and dying alone is perceived as an indicator of a bad death by staff and families in LTCHs (22). Pandemic related visiting restrictions may limit deathbed vigils. Where possible, in accordance with local public health guidelines, family presence should be facilitated.

#### **4. End-of-Life symptoms should be managed effectively**

Residents can present with a variety of symptoms and complications throughout their illness journeys. Symptoms may worsen and complications associated with co-existing advanced chronic illnesses such as advanced cancer, and end-stage heart, lung, and renal diseases often increase at the end of life. These symptoms include dyspnea, pain, agitation and delirium, anxiety and depression; and airway secretions, amongst many others. Many, such as pain and delirium, are often under-recognized and mismanaged (50–52). Delirium, which can be difficult at times to differentiate from coexisting dementia, can complicate the care and management of symptoms and increase safety concerns. Symptoms may progress gradually or, as with COVID-19 infection, progress rapidly, escalating within a few hours.

Person-centered care approaches are needed, informed by amongst others, the persons' life history and the clinical presentation (53). Optimal assessment and symptom management will reduce discomfort at the end-of-life and promote good death (17) and will relieve some stress for family members who may not be able to visit due to pandemic related restrictions. The general approach with most symptoms requires a meticulous assessment to identify the underlying causes and their impact on the resident.

**LTCHs should build and ensure capacity to optimally manage symptoms throughout the resident's illness and at the end of life when comfort measures take priority.** LTCHs should build capacity to optimally manage symptoms throughout the illness and at the end of life, when comfort measures take priority (10,17,61,20,54–60). Specific measures include:

- Adopting a proactive approach, including systematic and regular assessment of symptom severity and response to treatment, using validated and reliable tools (62). Several scales are available to assess pain even when residents are unable to self-report (63).
- Ability to make rapid changes in care plans and treatment regimens as condition changes.
- Access to palliative and geriatrics experts, not only to help build capacity but also, to aid or advise at any time (24/7) when symptoms are complex and difficult to manage. For example, when residents have intractable symptoms such as breathlessness and agitation that do not respond to usual approaches, and/or when palliative sedation is being considered for patients who are at the end of life(53,64).
- Establishing systems that support symptom assessment and management. For example, consider pre-printed orders (PPO) for managing end of life symptoms such as deprescribing guides (65,66) and the dying protocol PPO by Fraser Health in British Columbia (67). These require staff education as they may otherwise be applied inappropriately.

- Developing staff members' capacity to manage symptoms and ethical dilemmas; as well as challenges that may arise from conflicting values among or between staff and family members. For example, many people with advance dementia may stop eating at the very end of life due to inability to swallow. This often presents an ethical dilemma for staff and family members. In this stage of an illness, there is a strong body of evidence and experience that shows artificial feeding through enteral (tube feeding) or parenteral routes are not helpful and add considerable burden to the resident. However, care partners may be concerned about resident's suffering due to thirst and hunger that may prompt enteral feeding. Staff must be able to differentiate between residents who are unable to feed themselves from those who can no longer swallow and offer comfort oral feeding that can curb the feelings of hunger and thirst (68). Families should be educated and supported to consider risks and benefits.

**Staff in LTCHs should use best evidence for management of symptoms and complications related to advanced diseases and end-of-life.** Clinical guidelines and protocols for care management of palliative symptoms and complications related to advanced diseases are available.<sup>7</sup> These guidelines are not only relevant to care of patients with symptoms and complications caused by the SARS-CoV-2 virus (COVID-19 disease), such as breathlessness, coughing and delirium, they also apply to managing symptoms in residents who are not infected with the virus but whose end of life care is occurring in the context of a pandemic.<sup>8</sup> Opioids are the mainstay of treatment for severe symptoms such as pain and dyspnea, as well as coughing, including among patients who are opioid naïve (69). In addition, adjuvant therapy should be considered for concurrent symptoms such as shortness of breath, restlessness, agitation, and anxiety (69,70). Applying guidelines does not supersede clinical judgement and must take into consideration the circumstances of residents in LTCHs and their individual circumstances.

Palliative care guidelines provide guidance about dose adjustments and choice of opioid, use of adjuvants, and conditions that contraindicate use of particular adjuvants.

It is essential that non-pharmacological management be incorporated wherever possible (i.e., oxygen therapy via nasal prongs for hypoxia; cool sponging on face; positioning for comfort, to aid breathing, and for draining secretions; support for anxiety). LTCH staff, however, need to be attentive to the role of some of these approaches in the context of the COVID-19 pandemic and outbreak risk mitigation. The use of fans, for example, have been shown to be a useful approach to managing dyspnea at the end of life. However, this is an aerosolizing procedure that is contraindicated in a patient with proven or suspected SAR-CoV-2 virus (COVID-19 disease), as it amplifies the risk of viral spread (71).

**LTCHs should collaborate to ensure access to required medications, alternative treatment approaches, supplies, and personal protective equipment.** Significant medication shortages have been observed during the pandemic (72). These shortages have included medications that are used at end of life; including opioids such as morphine and hydromorphone, as well as, haloperidol, methotrimeprazine, midazolam, scopolamine, and dexamethasone, amongst others. Close collaboration is required between LTCHs and pharmacists to anticipate such shortages, be proactive to prevent them where possible, and where they do occur use alternative treatment approaches. LTCHs should also devise contingency plans where 24/7 access to pharmacies are

not available. LTCHs should have access to oxygen therapy and personal protective equipment, particularly in cases where certain therapies may risk aerosolizing the virus (70).

#### **5. After death care should be provided consistently with local public health guidelines and evidence about SARS-CoV-2 transmission**

Once the resident dies, a registered nurse (RN) or a registered practical nurse can pronounce death, as there is no legal requirement in Canada, that it is pronounced by a physician (73). However, a death certificate can only be completed by a physician or, in some jurisdictions, by a nurse practitioner (73). If the resident had confirmed or suspected diagnosis of COVID-19 infection, the LTCH should take specific measures informed by guidance from World Health Organization and their local public health authority.

Though so far there is no evidence of persons contracting COVID-19 infection from being exposed to the bodies of an infected individual, it is important that LTCH staff follow routine practices such as hand hygiene, use personal protective equipment during the last offices and cleaning of equipment and environment when having cared for a person with confirmed or suspected COVID-19 disease (74,75). A Point of Care Risk Assessment should be performed to gauge the risk of possible splatter from the resident's body fluids, in which case they should don fluid resistant PPE (76). Policies and procedures should be in place that guide LTCH staff in taking utmost care to respect the dignity, religious and cultural traditions of the residents while respecting and balancing rights of the family members (74). Finally, LTCHs should follow strict disinfecting and cleaning protocol, as human coronavirus can stay infectious for about many days on surfaces (77).

#### **6. Grief and bereavement support should be provided to family members of deceased residents, LTC home staff, and surviving LTC home residents, including residents with dementia.**

Disruptions to typical grief and bereavement experiences and support are characteristic of the pandemic. Staff are not able to provide the usual grief support or exercise usual rituals to acknowledge the passing and pay respects to the deceased. Probability of complicated or disenfranchised grief after the death of a LTC home resident during the pandemic is increased due to: (1) the unexpected nature of the death and rapid deterioration of residents who die from COVID-19; (2) inability to be with the resident and say goodbye (3) the context of experiencing multiple other losses and stressors associated with the pandemic that tax coping and diminish resources and supports for coping; (4) potential disruption of faith and of religious and spiritual practices due to restrictions on practices like gatherings and even being present with the person at death; (5) diminished social networks; and (6) lack of access to rituals, such as funerals, that help people process loss and grief (78–82)

**Support for residents with dementia** should be individualized. It should not be assumed that people with dementia do not notice or are unaffected by deaths of people around them (83,84). It may be helpful to acknowledge loss and involve residents with dementia in rituals as they are able.

**Rituals to mark the death of a resident** are important for family, staff, and residents. In addition to posting a memorial notice and photograph of the deceased resident other practices are accessible to residents who have dementia and are experienced by staff and family as respectful and dignified, (e.g, honour guard when the body leaves the building, including recognition of the loss at the next meal through a moment of silence, words of remembrance, and rose at the place of the deceased resident) (84). Monthly or semi-annual gatherings to mark residents' deaths could be replaced, while visiting is restricted, by virtual gatherings or memorial notices in newsletters.

**Support for bereaved families** from LTC homes should include: (1) timely notification of the death of the resident; (2) expressing sympathy (card immediately and phone call to check in about a month after the death); (3) providing information about post-death services (e.g., funeral homes); (4) providing written information about grief and supports including variability of normal grief experiences, potential disruption of grief because of pandemic restrictions, importance of drawing on their support networks, and bereavement support resources in their community. Primary care providers should be aware of increased risk for complicated grief and follow-up with the bereaved for at least 6 months after the death, providing support or referral as indicated (81,85).

**Support for staff** must acknowledge the intimate, close, often "family-like" relationships that care providers have with residents with dementia and their grief when residents die. Staff who work closely with a resident and are not present at the time of the death should be notified of the resident's death prior to their next shift. Staff need time to acknowledge and process loss after a death, which may mean a break from providing care for other residents. Supervisors should acknowledge the meaning of the loss. Opportunities to express sympathy for and say goodbye to residents' family members are important. Staff rely on support from peers to process grief. This can be supported formally through debriefing sessions and informal time to talk and reminisce following a death. Visiting restrictions increase risk for moral distress among grieving staff. In LTC homes that have COVID-19 outbreaks, the high numbers of deaths and potential for "bad deaths" also increases risk for moral distress and complicated bereavement. Additional mental health supports should be available (86).



## References

1. Government of Ontario. How Ontario is responding to COVID-19 [Internet]. 2020 [cited 2020 Aug 19]. Available from: <https://www.ontario.ca/page/how-ontario-is-responding-covid-19>
2. Statistics Canada. Census in brief: A portrait of the population aged 85 and older in 2016 in Canada, census year 2016 [Internet]. 2019 [cited 2020 Aug 19]. Available from: <https://www12.statcan.gc.ca/census-recensement/2016/as-sa/98-200-x/2016004/98-200-x2016004-eng.cfm>
3. Jayaraman J, Joseph K. Determinants of place of death: A population-based retrospective cohort study. *BMC Palliat Care*. 2013;12(1).
4. Canadian Institute for Health Information. Profile of residents in residential and hospital-based continuing care, 2017-2018 [Internet]. 2020. Available from: <https://www.cihi.ca/en/search?query=quick+stats+continuing+care&Search+Submit=>
5. Hoben M, Chamberlain SA, Gruneir A, Knopp-Sihota JA, Sutherland JM, Poss JW, et al. Nursing home length of stay in 3 Canadian health regions: Temporal trends, jurisdictional differences, and associated factors. *J Am Med Dir Assoc*. 2019;20(9):1121–8.
6. Kelly A, Conell-Price J, Covinsky K, Cenzer IS, Chang A, Boscardin WJ, et al. Length of stay for older adults residing in nursing homes at the end of life. *J Am Geriatr Soc*. 2010;58(9):1701–6.
7. Hirdes JP, Mitchell L, Maxwell CJ, White N. Beyond the “iron lungs of gerontology”: Using evidence to shape the future of nursing homes in Canada. *Can J Aging*. 2011 Sep;30(3):371–90.
8. Van Der Steen JT. Dying with dementia: What we know after more than a decade of research. *J Alzheimer’s Dis*. 2010;22(1):37–55.
9. De Gendt C, Bilsen J, Stichele R Vander, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium: A nationwide survey. *J Pain Symptom Manage*. 2013 Feb;45(2):223–34.
10. Hickman S, Unroe K, Ersek M, Buente B, Sachs G. Systematic advance care planning in the nursing home: Preliminary outcomes from the OPTIMISTIC (Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care) demonstration project (S790). *J Pain Symptom Manage*. 2016 Feb 1;51(2):457–8.
11. Towsley GL, Hirschman KB. Talking about end-of-life care: Perspectives of nursing home residents. *Geriatr Nurs (Minneap)*. 2018 Jan 1;39(1):72–6.
12. Aronson L. Ageism is making the coronavirus pandemic worse [Internet]. 2020 [cited 2020 Aug 19]. Available from: <https://www.theatlantic.com/culture/archive/2020/03/americas-ageism-crisis-is-helping-the-coronavirus/608905/>
13. Pittis D. Politicians who consider sacrificing the old for the sake of the economy face a backlash: Don Pittis | CBC News [Internet]. 2020 [cited 2020 Aug 19]. Available from: <https://www.cbc.ca/news/business/coronavirus-covid-economy-seniors-1.5510079>

14. Quality End of Life Care Coalition of Canada (QELCC). The Way Forward [Internet]. 2020 [cited 2020 Aug 19]. Available from: <http://www.hpcintegration.ca/>
15. Van Der Steen JT, Radbruch L, Hertogh CM, De Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014 Mar;28(3):197–209.
16. Phillips J, Davidson PM, Willcock S. An insight into the delivery of a palliative approach in residential aged care: The general practitioner perspective. *J Appl Gerontol.* 2009 Feb 9;28(3):395–405.
17. Thompson G, Wickson-Griffiths A. A palliative approach to care: From diagnosis to end of life. In: Garcia L, McCleary L, Drummond N, editors. *Evidence-Informed Approaches for Managing Dementia Transitions*. Cambridge, MA: Academic Press; 2020. p. 213–34.
18. Collingridge Moore D, Payne S, Van den Block L, Ling J, Froggatt K, Gatsolaeva Y, et al. Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. *Palliat Med.* 2020 May 1;34(5):558–70.
19. Kaasalainen S. Current issues with implementing a palliative approach in long-term care: Where do we go from here? *Palliat Med.* 2020 May 1;34(5):555–7.
20. Kaasalainen S, Sussman T, McCleary L, Thompson G, Hunter P V., Wickson-Griffiths A, et al. Palliative care models in long-term care: A scoping review. *Nurs Leadersh.* 2019 Sep 1;32(3):8–26.
21. Kaasalainen S, Sussman T, McCleary L, Thompson G, Hunter P V., Wickson-Griffiths A, et al. A stakeholder analysis of the strengthening a palliative approach in long-term care model. *Nurs Leadersh.* 2019 Sep 1;32(3):27–39.
22. Thompson G, Shindruk C, Wickson-Griffiths A, Sussman T, Hunter P, McClement S, et al. “Who would want to die like that?” Perspectives on dying alone in a long-term care setting. *Death Stud.* 2019;43(8):509–20.
23. Simard J. *The End-of-Life Namaste Care Program for People with Dementia*. Illinois: Health Professions Press, Inc.; 2013.
24. Kaasalainen S, Hunter P V, Dal Bello-Haas V, Dolovich L, Froggatt K, Hadjistavropoulos T, et al. Evaluating the feasibility and acceptability of the Namaste Care program in long-term care settings in Canada. *Pilot Feasibility Stud.* 2020;6(1):34.
25. Bunn F, Lynch J, Goodman C, Sharpe R, Walshe C, Preston N, et al. Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste Care and other multisensory interventions. *BMC Geriatr.* 2018;18(1):303.
26. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: A consensus definition from a multidisciplinary delphi panel. *J Pain Symptom Manage.* 2017 May 1;53(5):821–832.e1.
27. Cantor MD, Pearlman RA. Advance care planning in long-term care facilities. *J Am Med Dir Assoc.* 2004 Mar;5(Supplement):S73–80.

28. Ashton SE, Roe B, Jack B, McClelland B. End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – A qualitative study. *Dementia*. 2016 Sep 1;15(5):958–75.
29. Black BS, Fogarty LA, Phillips H, Finucane T, Loreck DJ, Baker A, et al. Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *J Aging Health*. 2009 Jun;21(4):627–50.
30. Elliott BA, Gessert CE, Peden-Mcalpine C. Family decision-making in advanced dementia: Narrative and ethics. *Scand J Caring Sci*. 2009 Jun;23(2):251–8.
31. Brinkman-Stoppelenburg A, Rietjens JAC, Van Der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliat Med*. 2014;28(8):1000–25.
32. Chen CY, Thorsteinsdottir B, Cha SS, Hanson GJ, Peterson SM, Rahman PA, et al. Health care outcomes and advance care planning in older adults who receive home-based palliative care: A pilot cohort study. *J Palliat Med*. 2015 Jan 1;18(1):38–44.
33. Poppe M, Burleigh S, Banerjee S. Qualitative evaluation of Advanced Care Planning in Early Dementia (ACP-ED). *PLoS One*. 2013 Apr 10;8(4).
34. Radwany SM, Hazelett SE, Allen KR, Kropp DJ, Ertle D, Albanese TH, et al. Results of the promoting effective advance care planning for elders (PEACE) randomized pilot study. *Popul Health Manag*. 2014 Apr 1;17(2):106–11.
35. Ke LS, Huang X, O'Connor M, Lee S. Nurses' views regarding implementing advance care planning for older people: A systematic review and synthesis of qualitative studies. *J Clin Nurs*. 2015 Aug 1;24(15–16):2057–73.
36. Litzelman DK, Inui TS, Griffin WJ, Perkins A, Cottingham AH, Schmitt-Wendholt KM, et al. Impact of community health workers on elderly patients' advance care planning and health care utilization. *Med Care*. 2017;55(4):319–26.
37. Adraine Labs & Conversation Starter Kit. Being prepared in the time of COVID-19: Three things you can do now. 2020.
38. Chan D, Livingston G, Jones L, Sampson EL. Grief reactions in dementia carers: A systematic review. *Int J Geriatr Psychiatry*. 2013 Jan;28(1):1–17.
39. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. *JAMA - J Am Med Assoc*. 2014;311(10):1052–9.
40. Bass DM, Judge KS, Lynn Snow A, Wilson NL, Looman WJ, McCarthy C, et al. Negative caregiving effects among caregivers of veterans with dementia. *Am J Geriatr Psychiatry*. 2012;20(3):239–47.
41. Beinart N, Weinman J, Wade D, Brady R. Caregiver burden and psychoeducational interventions in Alzheimer's Disease: A review. *Dement Geriatr Cogn Dis Extra*. 2012 Dec 17;2(1):638–48.
42. Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: Family caregiver burden. *J Adv Nurs*. 2007 Jun;58(5):446–57.
43. Sörensen S, Conwell Y. Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. *Am J Geriatr Psychiatry*. 2011;19(6):491–6.

44. Romero MM, Ott CH, Kelber ST. Predictors of grief in bereaved family caregivers of person's with Alzheimer's Disease: A prospective study. *Death Stud.* 2014;38(6):395–403.
45. Schulz R. Research priorities in geriatric palliative care: Informal caregiving. *J Palliat Med.* 2013 Sep 1;16(9):1008–12.
46. Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-Life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med.* 2003 Nov 13;349(20):1936–42.
47. Sussman T, Kaasalainen S, Lee E, Akhtar-Danesh N, Strachan PH, Brazil K, et al. Condition-specific pamphlets to improve end-of-life communication in long-term care: Staff perceptions on usability and use. *J Am Med Dir Assoc.* 2019;20(3):262–7.
48. Mendelsohn L, McCleary L. Reflections on working with families in long-term care during the SARS restrictions. *Perspectives (Montclair).* 2003;27(3):8–12.
49. McCleary L, Munro M, Jackson L, Mendelsohn L. Impact of SARS visiting restrictions on relatives of long-term care residents. *J Soc Work Long Term Care.* 2006;3(3–4):3–20.
50. Hall P, Schroder C, Weaver L. The last 48 hours of life in long-term care: A focused chart audit. *J Am Geriatr Soc.* 2002;50(3):501–6.
51. Oliver DP, Porock D, Zweig S. End-of-life care in U.S. nursing homes: a review of the evidence. *J Am Med Dir Assoc.* 2005;6(3 Suppl):S21-30.
52. Strumpf NE, Tuch H, Stillman D, Parrish P, Morrison N. Implementing palliative care in the nursing home. *Ann Long-Term Care.* 2004;12(11):35–41.
53. Canadian Coalition for Seniors' Mental Health. Guideline on the assessment and treatment of delirium in older adults at the end of life. 2010.
54. Hall S, Goddard C, Stewart F, Higginson IJ. Implementing a quality improvement programme in palliative care in care homes: a qualitative study. *BMC Geriatr.* 2011;11(1):31.
55. Parker D, Wilson J. *The Palliative Approach Toolkit Audits.* University of Queensland; 2015.
56. Lee J, Cheng J, Au K, Yeung F, Leung M, Ng J, et al. Improving the quality of end-of-life care in long-term care institutions. *J Palliat Med.* 2013 Oct;16(10):1268–74.
57. Unroe KT, Nazir A, Holtz LR, Maurer H, Miller E, Hickman SE, et al. The Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care approach: preliminary data from the implementation of a Centers for Medicare and Medicaid Services nursing facility demonstration project. *J Am Geriatr Soc.* 2015 Jan;63(1):165–9.
58. Parker D, Hodgkinson B. A comparison of palliative care outcome measures used to assess the quality of palliative care provided in Residential Aged Care Facilities: a systematic review. *JBIC Libr Syst Rev.* 2010;8(3):90–120.
59. Ouslander G. IS6.10: Crossing the border of the nursing home – reducing unnecessary hospitalizations of vulnerable older patients: the INTERACT program. *Eur Geriatr Med.* 2014;5:S10.

60. Vandenberg E V, Tvrđik A, Keller BK. Use of the quality improvement process in assessing end-of-life care in the nursing home. *J Am Med Dir Assoc*. 2006 Mar;7(3 Suppl):S82-7; 81.
61. Registered Nurses Association of Ontario. End-of-life care during the last days and hours. Toronto, ON: RNAO; 2011.
62. Khosravani H, Steinberg L. Symptom management and end-of-life care of COVID-19 residents in long-term care homes. *Canadian Family Physician*; 2020.
63. McGuire DB, Kaiser KS, Haisfield-Wolfe ME, Iyamu F. Pain assessment in noncommunicative adult palliative care patients. *Nurs Clin North Am*. 2016 Sep 1;51(3):397–431.
64. Cowan JD, Walsh D. Terminal sedation in palliative medicine definition and review of the literature. *Support Care Cancer*. 2001;9(6):403–7.
65. Stinson MJ, Gurevitz S, Carrigan A. Deprescribing at the end of life in older patients. *J Am Acad Physician Assist*. 2019 Jul 1;32(7):20–4.
66. Lavan AH, Gallagher P, Parsons C, O’Mahony D. STOPPFrail (Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy): Consensus validation. *Age Ageing*. 2017 Jul 1;46(4):600–7.
67. Fraser Health Authority. Actively dying protocol pre-printed order and form [Internet]. 2018 [cited 2020 Aug 23]. Available from: <https://www.fraserhealth.ca/employees/student-practice-education/student-practice-news/actively-dying-protocol-pre-printed-order-and-form#.X0JYmZNKi3I>
68. Arcand M. End-of-life issues in advanced dementia part 2: Management of poor nutritional intake, dehydration, and pneumonia. *Can Fam Physician*. 2015;61(4):337–41.
69. BC Centre for Palliative Care. Symptom management for adult patients with COVID-19 receiving end-of-life supportive care outside of the ICU [Internet]. 2020 [cited 2020 Aug 20]. Available from: <https://bc-cpc.ca/cpc/wp-content/uploads/2020/03/COVID-19-End-of-Life-Symptom-Management.pdf>
70. Pereira J, Barwich D, Nayar S. Managing dyspnea in patients with COVID-19. 2020.
71. The Australian & New Zealand Society of Palliative Medicine (ANZSPM) COVID-19 Special Interest Group. Essential palliative & end-of-life care in the COVID-19 pandemic [Internet]. 2020 [cited 2020 Aug 23]. Available from: <http://www.anzspm.org.au/c/anzspm?a=da&did=1005077&pid=1587788101>
72. Pereira J, Downar J, Arya A, Rice P, MacDonald S, Osborne E. Managing potential palliative care medication shortages during the COVID-19 pandemic: A guide provided by Pallium Canada. 2020.
73. Canadian Medical Protective Association. Completing medical certificates of death: Who’s responsible? [Internet]. 2019 [cited 2020 Aug 20]. Available from: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2016/completing-medical-certificates-of-death-who-s-responsible>
74. World Health Organization. Infection prevention and control for the safe management of a dead body in the context of COVID-19 [Internet]. 2020 [cited 2020 Aug 20]. Available

- from: [https://apps.who.int/iris/bitstream/handle/10665/331538/WHO-COVID-19-IPC\\_DBMgmt-2020.1-eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/331538/WHO-COVID-19-IPC_DBMgmt-2020.1-eng.pdf)
75. Public Health Agency of Canada. Routine practices and additional precautions for preventing the transmission of infection in healthcare settings [Internet]. 2017 [cited 2020 Aug 20]. Available from: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/routine-practices-precautions-healthcare-associated-infections.html>
  76. BC Centre for Disease Control. Safe handling of bodies of deceased persons with suspected or confirmed COVID-19 - Interim guidance [Internet]. 2020 [cited 2020 Aug 20]. Available from: [http://www.bccdc.ca/Health-Professionals-Site/Documents/COVID19\\_SafeHandlingBodies.pdf](http://www.bccdc.ca/Health-Professionals-Site/Documents/COVID19_SafeHandlingBodies.pdf)
  77. Kampf G, Todt D, Pfaender S, Steinmann E. Persistence of coronaviruses on inanimate surfaces and their inactivation with biocidal agents. *J Hosp Infect.* 2020 Mar 1;104(3):246–51.
  78. Bilgili GÖ. Mental health consequences of COVID-19 disaster. *Infect Dis Clin Microbiol.* 2020 Apr 30;2(1):42–5.
  79. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 pandemic: considerations for palliative care providers. *J Pain Symptom Manage.* 2020 Jul 1;60(1):e70–6.
  80. Morris SE, Moment A, Thomas J de L. Caring for bereaved family members during the COVID-19 pandemic: Before and after the death of a patient. *J Pain Symptom Manage.* 2020 Aug 1;60(2):e70–4.
  81. Mayland CR, Harding AJE, Preston N, Payne S. Supporting adults bereaved through COVID-19: A rapid review of the impact of previous pandemics on grief and bereavement. *J Pain Symptom Manage.* 2020 Aug 1;60(2):e33–9.
  82. Moore KJ, Sampson EL, Kupeli N, Davies N. Supporting families in end-of-life care and bereavement in the COVID-19 Era. *Int Psychogeriatrics.* 2020;1–11.
  83. Sussman T, Kaasalainen S, Mintzberg S, Sinclair S, Young L, Ploeg J, et al. Broadening end-of-life comfort to improve palliative care practices in long term care. *Can J Aging.* 2017 Sep 1;36(3):306–17.
  84. McCleary L, Thompson GN, Venturato L, Wickson-Griffiths A, Hunter P, Sussman T, et al. Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry.* 2018 Sep 24;18(1).
  85. Eisma MC, Boelen PA, Lenferink LIM. Prolonged grief disorder following the Coronavirus (COVID-19) pandemic. *Psychiatry Res.* 2020 Jun 1;288.
  86. Maben J, Bridges J. Covid-19: Supporting nurses' psychological and mental health. *J Clin Nurs.* 2020 Aug 1;29(15–16):2742–50.
  87. Palliative Alliance. Quality palliative care in long term care: Applying the Kelley Model for community capacity development [Internet]. 2017 [cited 2020 Aug 20]. Available from: <http://www.palliativealliance.ca/applying-the-kelley-model-for-community-capacity-development>

88. Pereira J, Chary S, Moat JB, Faulkner J, Gravelle-Ray N, Carreira O, et al. Pallium Canada's curriculum development model: A framework to support large-scale courseware development and deployment. *J Palliat Med.* 2020 Jun 1;23(6):759–66.

### End Notes

- 
- <sup>i</sup> e.g., Kelley Model for Community Capacity Development (87).
- <sup>ii</sup> e.g., (a) Pallium Canada's LEAP-LTC (<https://www.pallium.ca/course/leap-long-term-care/>), Online LEAP modules are currently offered free-of-charge during COVID-19(88); (b) Foundations of Palliative Care Course for Frontline Staff, Centre for Education and Research on Aging and Health (<http://cerah.lakeheadu.ca/palliative-care-for-frontline-workers-/>); (c) Quality Palliative Care in Long Term Care Toolkit (<http://www.palliativealliance.ca/qpc-ltc-toolkit>); (d) Fundamentals of Hospice Palliative Care (<https://acclaimhealth.ca/programs/palliative-care-consultation/education/fundamentals-of-hospice-palliative-care/>)
- <sup>iii</sup> Speak Up Canada. (n.d.). *Advance Care Planning in Canada.* <https://www.advancemcareplanning.ca/>
- <sup>iv</sup> Speak Up Ontario. (2020). *COVID-19 Resources.* <https://www.speakupontario.ca/>
- <sup>v</sup> e.g., **Palliative Care Guidelines:** (a) Pallium Canada's Palliative Pocketbook and App (<https://www.pallium.ca/mobile-app-pocketbook/>); (b) Palliative EZ Guide, McMaster Palliative Care Symptom Management Guide and App Pocketbook and App (<https://palliativeezguide.ca/>); (c) British Columbia Centre for Palliative Care and Division of Palliative Care, University of British Columbia Guidelines (<https://bc-cpc.ca/cpc/publications/symptom-management-guidelines/>); (d) Fraser Health, British Columbia Palliative Care Guidelines (<https://www.fraserhealth.ca/employees/clinical-resources/hospice-palliative-care#.XvJEsmhKjn0>)
- <sup>vi</sup> e.g., **COVID-19 Palliative Care Guidelines:** (a) McMaster Palliative Care COVID-19 Symptom Guidelines (Division of Palliative Care): Managing Dyspnea (<https://fhs.mcmaster.ca/palliativecare/documents/McMasterDyspneaProtocolCOVIDHamilton31March2020.pdf>); (b) McMaster Palliative Care COVID-19 Symptom Guidelines (Division of Palliative Care): Other Symptoms (<https://fhs.mcmaster.ca/palliativecare/documents/McMasterSymptomManagementProtocolsCOVID31March2020.pdf>); (c) McMaster Palliative Care COVID-19 Symptom Guidelines (Division of Palliative Care): Palliative Sedation Pandemic Protocol (<https://fhs.mcmaster.ca/palliativecare/documents/McMasterPalliativeSedationProtocolCOVID31March2020.pdf>); (d) Fraser Health and Division of Palliative Care University of British Columbia Guidelines on Managing Dyspnea (<https://bc-cpc.ca/cpc/wp-content/uploads/2020/03/COVID-19-End-of-Life-Symptom-Management.pdf>)