

Providing Palliative and
End-of-Life Care for
Residents in Long-Term Care
During the COVID-19 Pandemic

RESOURCE TOOLKIT

Providing Palliative and End-of-Life Care for Residents in Long-Term Care

Long-term Care (LTC) homes typically provide palliative and end of life care for residents, unless a resident has complex needs that require intensive or complicated medical assistance. This toolkit was developed to complement existing processes and procedures, and provide additional support to LTC leaders and providers providing palliative and end-of-life care in the context of COVID-19. The included resources provide practical information to help with communication and care planning, symptom management and pre- and post-death support for families as well as health care professionals during the pandemic.

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Goals of Care Discussions

What do we know about Goals of Care discussions in the context of COVID-19?

Worries about risks of contracting COVID-19 are shared by residents, families and health care providers. While a focus on prevention measures are of paramount importance, it is also an appropriate time to further engage the resident in conversations to explore their wishes and values. Understanding what the resident considers important, and identifying their goals of care will help guide care decisions if a resident's health status were to change - due to COVID-19 or any other serious illness.

We know that most of the time, robust advance care planning conversations have not happened between a resident and their future substitute decision maker (SDM). Despite this, health care providers are finding that when they talk about the current pandemic situation, residents are usually clear about what matters most to them when they imagine their own serious illness or dying process in these unusual circumstances. Often they will state that they know that they are at a risk of getting the virus - and possibly dying from it - and would like to talk about "what if" situations. Taking a proactive approach can provide residents and their substitute decision makers with reassurance that their wishes are known and understood.

The following tools are designed to help you facilitate discussions with capable residents (or their SDMs, if they are incapable), proactively, whenever that is possible.

RECOMMENDED RESOURCES

Advance Care Planning –Education Resources for Residents and Substitute Decision Makers

Engaging in Advance Care Planning for COVID-19 – Information for Residents

<https://www.speakupontario.ca/wp-content/uploads/2020/04/Engaging-in-Advance-Care-Planning-for-COVID-19.pdf>

Engaging in Advance Care Planning for COVID-19 – Information for Substitute Decision Makers

<https://www.speakupontario.ca/wp-content/uploads/2020/04/Information-for-a-Substitute-Decision-Maker-for-Covid-19.pdf>

Goals of Care Discussion Guides - for Health Care Providers

General Goals of Care discussion – with concerns about COVID-19

<https://www.speakupontario.ca/wp-content/uploads/2020/04/GOC-FECoMo-COVIDNeg.pdf>

Goals of Care planning if the resident has Severe COVID-19 illness

<https://www.speakupontario.ca/wp-content/uploads/2020/04/GOC-FECoMo-COVIDSevere-LTC-3.pdf>

Goals of Care planning if the resident has Mild/Moderate COVID-19 Illness

<https://www.speakupontario.ca/wp-content/uploads/2020/04/GOC-FECoMo-COVIDMild-LTC-2.pdf>

Symptom Management

Older adults are more likely to experience chronic diseases and disabilities, as well as immune dysfunction, hence we have seen that COVID-19 disproportionately affects this population.^{1,2} In particular, older adults are more susceptible to the infection and are more likely to suffer from the severe form of COVID-19 disease and to have complications³. The understanding of how COVID-19 symptoms present in the population of older adults continues to evolve.

What do we know about COVID-19 Symptoms in older adults?

Symptoms may present differently in older adults. Research has found that typical symptoms of COVID-19 - **fever, cough, and dyspnea** - may be absent in the elderly.² Atypical symptoms of COVID-19 in older adults may include **delirium, falls, generalized weakness, malaise, functional decline, conjunctivitis, anorexia, increased sputum production, dizziness, headache, rhinorrhea, chest pain, hemoptysis, diarrhea, nausea/vomiting, abdominal pain, nasal congestion, and anosmia**.^{1,2,4}

It has been found that the probability of atypical presentation can be related to older age, frailty, and increasing number of comorbidities. It is important to note that older adults may also present with mild symptoms that are disproportionate to the severity of their illness.^{2,4}

What symptom management approaches can be most helpful during the pandemic?

Two symptoms may be more challenging to manage in residents: delirium and respiratory distress. These would be a key focus for providing palliative care in Long-Term Care homes. If the resident's needs become more complex, it may be necessary to engage a palliative care specialist for consultation, advice and/or mentorship.

Delirium

Delirium is an altered state of consciousness that can manifest as an acute confusional state or a hypo-active, less responsive state. Delirium is common in COVID-19 infections, and may be a symptom at presentation and/or during management. Delirium may precede onset of other symptoms. COVID-19-related pneumonia and acute respiratory distress syndrome (ARDS) are severe conditions that increase the risk for delirium, in addition to the common medical scenarios (e.g. dehydration, pain, hyper/hypoglycemia, medications, etc) that exist in LTC. Agitation or increased sedation may make management including delivery of care and reducing the risk of cross-infection more challenging.

RECOMMENDED RESOURCES

Prevention, Management and Communication Resources for Delirium

Considerations for Preventing and Managing Delirium in Older Adults during COVID-19 Pandemic, Across the Care Continuum

<https://www.rgptoronto.ca/wp-content/uploads/2020/04/COVID-19-Prevention-and-management-of-delirium-in-older-adults.pdf>

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Communication Tips for Clinicians Caring for Older Adults Experiencing Delirium during the COVID-19 Pandemic

<https://www.rgptoronto.ca/wp-content/uploads/2020/04/COVID-19-Communication-tips-for-clinicians-caring-for-older-adults-experiencing-delirium.pdf>

Breathlessness

Breathlessness is one of the main presenting symptoms of COVID-19. When breathlessness becomes severe, it can indicate pneumonia or acute respiratory distress syndrome (ARDS). Breathlessness is a distressing, multidimensional sensation and it can have a considerable emotional component. Breathlessness can be a very frightening symptom, even in milder cases.⁵

Approaches to managing respiratory distress:

- Identify and treat underlying causes of breathlessness
- Implement non-pharmacologic approaches
- Assess the need for medications to assist with reducing the distress associated with breathlessness (please refer to the resource link provided below)

Non-pharmacological approaches include:

- Breathing techniques and positioning during breathlessness episodes
- Relaxation techniques or a relaxation DVD
- Cooling the face, especially around the nose, may help reduce the sensation of breathlessness.⁵

In the context of COVID-19, fans should not be used, as they risk spreading droplets from the infected person.⁵

Caution is also important when using the following, as these interventions may generate aerosolized SARS-CoV2 virus particles:

- Humidified air/oxygen
- Oxygen flow greater than 4 - 6L/min
- High-flow nasal cannula
- Continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP)
- Nebulized treatments (bronchodilators, epinephrine, saline solutions etc.)

RECOMMENDED RESOURCE

Management of Respiratory Distress and End-of-life Care in COVID-19

<https://www.speakupontario.ca/wp-content/uploads/2020/04/Mgmt-of-Respiratory-Distress-EOL-Care-in-COVID-19-Residents-in-LTC-Homes.pdf>

What are the considerations for End-of-Life Care in the context of COVID-19?

Residents who are entering the last days to hours of their lives may have some additional symptoms that need to be addressed. The resident's level of alertness and ability to swallow will diminish. There is a need at this

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point to review their medications and discontinue those that are no longer needed and switch medications that are needed to manage symptoms to alternate forms (subcutaneous or sublingual).

Some residents who are dying of COVID-19 lung disease may have severe symptoms with rapid decline⁶. The clinical profile for these individuals is likely to include:

- High breathlessness / ‘air hunger’
- High distress
- High delirium / agitation
- High fever
- Risk of cessation of life over a short number of hours.

It is important to deliver effective medications, at effective doses, from the outset. Early management of symptoms will be the most effective way to reduce suffering⁶.

RECOMMENDED RESOURCE

Symptom Management for Adult Patients with COVID-19 Receiving End-of-life Supportive Care Outside of the ICU

<https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/EndOfLifeSymptomManagement-COVID19.pdf>

Supporting Families through Loss, Grief and Bereavement

What matters most to families right now?

Residents and families are facing a number of unique losses due to the COVID-19 pandemic, including the ability to have a face-to-face visit (and to provide comfort and companionship); the sense of safety from potential illness; and the freedom to engage in usual activities. These circumstances can result in feeling a loss of control, and increased fear and frustration.

Families are unable to visit with their family member, and are relying on members of the care team for updates and information. When the resident approaches end-of-life, key areas of focus for communicating with the family include:

- Providing clear and frequent information about their family member’s condition and their comfort level
- Instilling confidence that their family member is receiving care (to address all physical and medical needs) AND being cared for (focused on person-centeredness, comfort and dignity)
- Providing an opportunity for communication with their family member whenever this is possible via phone and/or video communication
- Helping with saying goodbye from a distance, if they are not permitted to have a final visit

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What does grieving look like for those who are coping with a loss during the pandemic?

We need to expect that the nature of loss and grief during this time will have some unique complexities. Not being able to be with their family member before and at the time of death will be very difficult for many individuals. There are also risks that may lead to complicated grief for some family members, including that many are dealing with higher levels of anxiety during this uncertain time, receiving less social support, and may experience lack of preparation for the death. Complicated grief can be mitigated by ensuring communication and compassionately sharing information, based on how much the individual would like to know, about the resident's final hours and minutes. Consider what reassurance they need about the care that was given.

Families may also have questions about what will happen after death - and what will be possible in terms of funeral and burial planning. (The Bereavement Authority of Ontario website is a source of current information and directives.)

What can you do to support someone who is grieving the loss of a family member?

Tips when interacting with a family member who is grieving:

- Prepare for the conversation. You may have been interacting with many grieving individuals, but being fully present for this individual is important and will take some time.
- Share your memories about the resident, and acknowledge the relationship that they had with their family member(s).
- Remember that anger is a normal emotion in grief, and may be further complicated by feelings of blame - or even guilt - about the circumstance

Recognize the challenging factors that impact grieving due to the current COVID-19 pandemic:

- Social / physical distancing practices restrict important in-person rituals and gatherings (like funerals, celebrations of life) with people in their own close circle that are normally a part of the ways we engage in memorializing, reminiscing, and coming to terms with the loss.
- Grieving in physical isolation means that those who are bereaved need to draw on virtual social connections. Reaching out can be hard in the midst of grief. Many older adults, who may also be living in isolation or in a care setting, may have more limited access to options for this mode of connecting. There are also limited distractions from their grief – as we are surrounded by pandemic information, which will be constant reminders of the loss.

Approaches that may be helpful in this circumstance:

- Creating a plan for a bereavement follow up to ensure the family is accessing help if needed can be invaluable.
- Loss during this pandemic is a shared experience with so many others. Sharing the loss with others through online or other virtual forums (like a virtual bereavement support group) may be helpful.

RECOMMENDED RESOURCES

Communication - Finding the right words

Specific Phrases & Word Choices that Can Be Helpful When Dealing with COVID19

Anne Kelemen, LICSW, APHSW-C, Terry Altilio, LCSW, APHSW-C, Vickie Leff, LCSW, APHSW-C

<https://img1.wsimg.com/blobby/go/2ad29bfa-43d6-4d9d-a3fe-a5abe1cb2c1f/downloads/SIC%20COVID%20Guidelines.pdf?ver=1585741689050>

Resources to Support Caregivers during COVID-19

Ontario Caregiver Organization

Caregiver Tips and Resources, including access to online Peer Support Groups

<https://ontariocaregiver.ca/covid-19/>

Government of Ontario

Information about services and programs available to support mental health and wellbeing

<https://www.ontario.ca/page/covid-19-support-people#section-4>

Resources for Bereaved Persons:

Bereaved Families of Ontario (Ontario)

Group support, one-to-one sessions and telephone support is available. Contact your local BFO office.

<http://www.bereavedfamilies.net/>

MyGrief.ca

An online resource to help you understand your grief and work through some of the difficult issues you may be facing. It has been developed by a team of national and international grief experts together with people who have experienced significant loss in their own lives. www.Mygrief.ca

Kidsgrief.ca

A free online resource to help parents support their children when someone in their life is dying or has died. It equips parents with the words and confidence needed to help children grieve life's losses in healthy ways.

Supporting Health Care Professionals during the Pandemic

What can we expect health care professionals to experience during a crisis?

Stress responses

COVID-19 is putting tremendous responsibility onto health care professionals. Professionals working in an emerging and /or prolonged crisis will likely experience their own stress response as a result of needing to adapt to changes and disruption to usual routines and ways of working.

Stress responses can become heightened when health care professionals witness the needs of others who are experiencing a traumatic circumstance. In some settings, they may suddenly be caring for a much higher number

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of residents in physical and emotional distress. They may be responding to a much higher level of stress and anxiety from family members seeking information and reassurance that their family member is safe. They may also be caring for more dying residents than usual, with a more rapid trajectory of physical decline. Professional grief - a normal response - may go unrecognized. Because of the unique circumstances, special rituals or practices that allow staff to recognize the loss of a resident may not be able to be observed during this time. Additionally for some individuals, their usual ways of coping with loss (self-care routines – such as exercising, spending time with family and friends) and finding resilience may be challenged under these extreme circumstances.

Risks of moral distress

The concept of moral distress⁷ can be present when a health care professional knows the right thing to do, but situational or other constraints make it nearly impossible to follow the right course of action. During the current pandemic, care providers may be experiencing moral distress related to:

- Having to enforce strict visiting restrictions
- Wishing one could be able to do more for a resident or family
- Working in resource constrained situations (increased staff – resident ratios) that do not allow for meaningful interactions with each resident
- Feeling distracted and not being fully present with residents due to own worries or concerns
- The physical demands of working while wearing personal protective equipment (PPE) which creates barriers to communication and touch.

If unaddressed, distress can lead to decisions to leave a job, increased mental health needs, and professional burnout. Having support and reassurance around the circumstances is important. If you are experiencing stress associated with the COVID-19 Pandemic, you are not alone, and help is available.

RECOMMENDED RESOURCES

Information

Fact Sheet: Emotional and Psychological Challenges Faced by Frontline Health Care Providers During the COVID-19 Pandemic

<https://cpa.ca/psychology-works-fact-sheet-emotional-and-psychological-challenges-faced-by-frontline-health-care-providers-during-the-covid-19-pandemic/>

Self-directed support and Self-care/Coping Tips

Mental Health and COVID-19 Resources for Health Care Workers

The Centre for Addiction and Mental Health (CAMH) has collated mental health and addiction supports for health care workers who might be impacted by the COVID-19 pandemic. Their website includes resources for provider self-care and distress management. <https://www.camh.ca/en/health-info/mental-health-and-covid-19/information-for-professionals>

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Psychosocial and Spiritual Supports for Health Care Workers

Hospice Palliative Care Ontario has offered a series of topics related to 'Psychosocial and Spiritual Support During COVID-19'. Recordings of these online Sessions on topics related to Emotional, Spiritual & Compassionate Care can be found at: <https://www.hpcoc.ca/psychosocial-spiritual-support>

Tips for Self-Care:

It can be difficult to draw on the usual activities that help to relieve stress during social distancing and disrupted work schedules. Using focused relaxation techniques and mindfulness practices can help to decrease stress, increase resilience, improve personal productivity, develop connections with others, and augment the ability to experience more joy and peace.

A quick search online for “relaxation techniques for stress relief” will yield many options to introduce you to these practices and identify a range of instructional video/audios. Finding a technique that feels like a good fit for you to try – and practice at – is what is important

Confidential counselling and Support

Services and Information to Support Wellbeing

The Government of Ontario has collated resources to help support mental health and wellbeing. Supports include connecting with peers for mental health support, self-led telephone or online therapy for stress, anxiety and depression, and Internet-Based Cognitive Behavioural Therapy (iCBT)

https://www.ontario.ca/page/covid-19-support-people?_ga=2.116164800.792932407.1588776500-780208104.1588776500#section-4

Employee Assistance Programs (EAPs)

Support services may be available through your employer – ask your benefits coordinator about your EAP.

Private Counselling

A number of Psychologists have volunteered free services during the pandemic and this list is available through <https://cpa.ca/corona-virus/psychservices/>

How can leaders support health care professionals experiencing distress?

These are unprecedented times that are putting extra pressure on LTC homes and team members. Reaching out for consultation from palliative care specialists can provide important supports and reassurance for the team as well ensuring best possible symptom management and comfort care for residents during the pandemic.

Promoting strong teamwork, clear communication and prioritization of workload is important in a prolonged crisis state. Extra effort to acknowledge strengths in what is working and promptly addressing staff needs for focused support is invaluable. Leaders can make sure that supports are in place and actively encourage self-care practices. Maintaining time for breaks, acknowledging efforts, and providing opportunities for debriefing are also important.

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RECOMMENDED RESOURCES

Supports for LTC Leaders and Team Members during COVID-19

The Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI) has a webpage for sharing new and existing supports for long-term care leaders and team members. Supports include resources for the health and well-being of team members, resources for the health and well-being of residents, supports for LTC staffing, and LTC orientation for incoming support.

<https://clri-ltc.ca/covid19/>

ECHO Care of the Elderly for LTC: COVID-19

Participate in an online session with peers to learn about ways to build resilience and maintain wellness through lectures and case-based discussions. This can be helpful to leaders in LTC who would like to connect with other homes. Online sessions are offered weekly and are recorded for future viewing.

<https://clri-ltc.ca/resource/echo-covid19/>

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