

Extract of :

Caring for Long Term Care Residents During COVID-19 Pandemic: A Guide to Managing Symptoms and End-of-Life Care

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Caring for LTC Residents During COVID-19 Pandemic: A Guide to Managing Symptoms and End-of-Life Care

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Planning Ahead for COVID-19:

A Resource for Families of Long-Term Care Residents

This resource was adapted with kind the permission of the Palliative and Therapeutic Harmonization (PATH) Program and the NSHA-Central Zone Frailty Strategy. For more information on PATH go to: pathclinic.ca

THESE ARE STRESSFUL TIMES

The COVID-19 pandemic situation is changing daily. Having a family member or loved-one in a nursing home during this time can give rise to anxiety, worry and many questions. This resource has been developed for family members and substitute decision-makers (SDMs) of older adults living in nursing homes. We're hoping that by providing accurate and practical information, we can help empower you to make the most appropriate medical decisions.

This resource offers information to help you:

- Understand the impact of COVID-19 on older adults living in nursing homes
- Know how to plan ahead and make decisions, should your family member contract COVID-19 (or another serious health issue) during the pandemic

COVID-19 IN OLDER ADULTS

Let's review some information about COVID-19 and older adults:

- Symptoms of COVID-19 can include cough, fever, difficulty breathing, and sudden onset of confusion (delirium)
- Older adults living in nursing homes are at very high risk of being affected by COVID-19 as well as suffering from complications, including death
- Our understanding of these risks comes from information from nursing homes who have already seen an outbreak

The outbreak of COVID-19 in a nursing home in Kirkland, Washington resulted in 101 of the 130 residents becoming infected with the virus within 11 days. As of March 18th, 55% of the infected residents had required hospitalization, and 34% had died.

(New England Journal of Medicine, March 27, 2020)

There is currently no vaccine to prevent COVID-19 and no specific treatment to cure the infection once it occurs



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YOUR ROLE AS DECISION MAKER

Although there are exceptions, most nursing home residents rely on another person—a substitute decision-maker—to make decisions in their best interest. The substitute decision-maker is a very important person in the resident’s circle of care and should be involved in all health care discussions and decisions. SDMs are legally bound to make decisions that are in keeping with what they believe the person would want in any given situation.

You may have already addressed your family member’s “goals of care” with the nursing home staff but the COVID-19 pandemic is a good opportunity to make sure that these goals of care fit with the special situation of the coronavirus pandemic. Thinking about health before the outbreak can help.

FRAILITY

You likely have heard the term “frailty” but what does it mean? Frailty can be thought of as the stage of life that begins when health issues affect independence with daily activities. As health issues and stressors accumulate, frailty progresses in stages (mild → moderate → severe → very severe).

- Every older adult living in a nursing home is frail and most are severely frail
- Being frail makes one more vulnerable to illness and injury and affects the ability to recover from illness—as frailty progresses, treatments for issues like COVID-19 become less effective
- Improving each person’s experience of frailty means carefully selecting those medications and treatments that are most likely to improve quality of life
- Knowing the stage of frailty and what to expect in the future can help with decision making

FRAILITY AND DEMENTIA

When problems with memory and thinking start to interfere with day-to-day life, this is called dementia. Dementia is a common cause of frailty but is often unrecognized. Alzheimer’s disease and strokes are the most common causes of dementia. About 65% of older adults in nursing homes have dementia, with likely more not yet formally diagnosed.

Dementia has several effects that include:

- Decreased quality of life
- Progressive worsening over time
- Changes in how well a person responds to treatments for other health issues
- Inability (in most cases) to make complex medical decisions for themselves, particularly during a health crisis

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WHAT DOES THIS ALL MEAN?

Over the next few weeks, you may be contacted by the healthcare team to make a plan about what to do if your family member contracts COVID-19. Now that you're familiar with the concepts of frailty, dementia, and the effects of COVID-19 on older adults in nursing homes, let's discuss some things to keep in mind:

- For older adults in nursing homes, the risk of dying from COVID-19 is high—over 30% in the Washington state nursing home
- If the person is not responding to oxygen through nasal prongs, the chance that they will survive is much lower
- If there is survival, overall health status and quality of life will likely be worse following the infection
- Treatment can involve suffering, which can be a significant burden, particularly when full recovery is not expected. We often think of physical pain when we think of suffering, but other kinds of suffering include:
 - Transfer to and from the hospital or emergency department
 - Being cared for by strangers in an overstressed situation
 - Being isolated during a time when visitors may not be permitted in nursing homes and hospitals
 - Changes in ability to eat familiar or enjoyable foods
 - Difficulty communicating due to problems with vision or hearing (especially when care providers wear protective masks)
 - Further loss of mobility
 - Delirium, which is the sudden worsening of memory and thinking. When people who are frail become ill, delirium is common and frequently results in permanent worsening of memory
- In severe frailty or advanced dementia, surviving COVID-19 generally means prolonging the time spent being more dependent on others and with reduced quality of life

During this pandemic, it is important to make medical decisions that consider the impact of frailty and/or dementia on recovery

CONSIDERING THE OPTIONS

There are three options for care in COVID-19. Regardless of the option chosen distressing physical symptoms such as fever and shortness of breath can be managed:

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OPTION	WHAT IS INVOLVED
<p>1. ESCALATE CARE</p>	<p>The goal is to lengthen life and could involve one or more of the following:</p> <ul style="list-style-type: none"> ● Transfer to hospital ● Oxygen ● Intravenous fluids ● Use of ventilator/breathing machine <p>Some treatments may be available in the nursing home while others may only be available in hospital.</p> <p>Once a breathing machine is needed, the outcome with frailty is generally very poor. Treatment will likely cause more suffering than benefit.</p> <p>It is important to remember that available treatments may vary by area and over time as the pandemic evolves. Therefore, the ability to hospitalize and/or use a breathing machine will depend on whether the service is available.</p>
<p>2. TREAT IN PLACE – NO ESCALATION</p>	<p>This care option involves:</p> <ul style="list-style-type: none"> ● Treatments that are available in the nursing home with a goal of supporting recovery ● If infection progresses, the care would shift to a focus on comfort, in the nursing home rather than transferring to hospital.
<p>3. COMFORT CARE ONLY</p>	<p>This care option includes:</p> <ul style="list-style-type: none"> ● Relieving breathlessness and other symptoms ● Avoiding transfer to hospital ● Minimizing unnecessary tests and treatment ● Aiming to allow family presence at the end of life where possible <p>Depending on current quality of life, severity of infection, and the values of the resident and family, sudden illness in a nursing home may present an opportunity for a comfortable death, in a familiar setting</p>

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TALKING WITH YOUR HEALTH CARE TEAM

When discussing treatment options for COVID-19, some questions to ask the health care team include:

- What is the person's frailty level?
- What is contributing to frailty (i.e. medical conditions, physical impairment, and/or impaired memory)?
- Is there dementia, and what is the current stage?
- What treatment options are currently available in the facility; in hospital?
- What do these options mean for future health function?
- What treatments are recommended?

The care your family member receives is priority. Although discussing goals of care for your loved one is stressful and difficult, it is important for you to feel equipped with the right information so that you can make the most appropriate decisions.

Together, you and the care team can ensure your loved one receives the best care possible.

ADDITIONAL RESOURCES:

Understanding Frailty: <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1645.pdf>

Stages of Frailty: <https://www.nshealth.ca/sites/nshealth>

COVID-19 Goals of Care Discussions for Long-Term Care Residents:

A Resource for Providers

This resource was adapted with kind the permission of the Palliative and Therapeutic Harmonization (PATH) Program and the NSHA-Central Zone Frailty Strategy. For more information on PATH go to: pathclinic.ca

THIS IS A CHALLENGING TIME: PREPARATION WILL HELP

During the coronavirus (COVID-19) pandemic, frail long-term care facility residents are at risk for severe and fatal disease. This document outlines the specific impact of COVID-19 for older long-term care facility residents. It provides an approach to goals of care discussions with the resident's substitute decision-makers (SDMs) and outlines the information needed to inform these discussions.

A corresponding printable worksheet is available titled: **DISCUSSING GOALS OF CARE: A WORKSHEET FOR HEALTH CARE PROVIDERS IN LTC** that provides a step by step guide to advance care planning, as well as an information sheet for SDMs: **PLANNING AHEAD FOR COVID-19: A RESOURCE FOR FAMILIES IN LONG TERM CARE CENTRES**.

Advance-care planning as a critical part of caring for long-term care facility residents during the pandemic. We hope this resource and the companion documents provide the guidance you need to carry out difficult but necessary conversations.

WHO REQUIRES UPDATED GOALS OF CARE?

The following situations may require updated goals of care:

- recent admission to long-term care (LTC) or when the resident does not have a care plan
- the current care plan indicates a preference for hospital-based or intensive care during illness
- when there are recent changes in health (new diagnosis of chronic illness or recent hospitalization)

PREPARE FOR THE CONVERSATION

STEP 1: Familiarize yourself with local pandemic protocols

Before discussing the issues with SDMs, become familiar with updated treatment policies in your area. Be informed about the types of care that can be delivered in long-term care (LTC) and the criteria for hospital and ICU transfer, which may continue to evolve.

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STEP 2: Identify the substitute decision-maker (SDM) and review previously documented goals of care

Some long-term care residents are able to make their own health care decisions; the resident’s SDM should be involved in the conversation, even when residents are cognitively intact because delirium may limit the resident’s capacity to participate in decision making during infection with COVID-19.

Individuals with dementia generally lack capacity to make complex medical decisions. Having residents participate in the decision-making process when they don’t have capacity to understand the context can be stressful for the resident and the SDM. Therefore, in this circumstance, offer the SDM the opportunity to speak privately.

Encourage the SDM to review the previous document titled: *PLANNING AHEAD FOR COVID-19: A RESOURCE FOR FAMILIES OF LONG-TERM CARE RESIDENTS*.

This resource describes frailty, dementia, and COVID-19 to help decision-makers understand and consider these concepts before making care decisions. The content mirrors the content of this document.

The resident and or SDM may have already undertaken and documented care planning which can be used to guide this discussion.

STEP 3: Determine resident’s up-to-date frailty level and dementia stage (if applicable)

Frailty is a stage of life that begins when the accumulation of health issues deplete physiologic reserve to the point that day-to-day activity is affected. Frailty generally progresses in stages. To stage frailty, consider which descriptors apply to your resident (see table below). You’ll also find this table in the worksheet.

Stage (Clinical Frailty Scale)	What function looks like	What cognition may look like (if dementia is present)
Moderate (6)	Any of the following: <ul style="list-style-type: none"> ● Needs reminders to change clothes or bathe but once reminded, can do the steps independently ● Needs hands-on help with stairs or getting into the tub 	Has difficulty naming the Canadian Prime Minister or United States President

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Severe (7)	Any of the following: <ul style="list-style-type: none"> • Needs hands-on help from staff for bathing and dressing • Needs help from staff for walking or transferring 	Has trouble naming first degree relatives
Very Severe (8)	Any of the following: <ul style="list-style-type: none"> • Completely dependent on staff for all personal care • Mostly confined to a bed or wheelchair 	Speaks very few words

As you can see, **every older adult who lives in a long-term care facility is frail**. Most are severely frail. Remember, dementia is a common and under-recognized cause of frailty.

STEP 4: Consider the frailty cycle



- Frail individuals will eventually experience a health crisis; the sudden worsening of an existing problem or the development of a new health issue (such as COVID-19)
- The more frail the resident is at the onset of the health crisis, the more likely survival will mean incomplete recovery and further frailty. This is the frailty cycle. Most residents will experience this cycle several times in the long-term care facility. Active treatment for COVID-19 is expected to follow this same pattern.

During each health crisis, if living with further dependence or reduced quality of life is not compatible with the resident’s known values, there is the option to manage the crisis by focusing on symptom management or palliative care.

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STEP 5: Know the risks of COVID-19 in this population

Here are some facts from the Centre of Disease Control and local research to consider:

1. In general, any acute deterioration in health with frailty poses risk. How much risk? In a local study, patients with severe or very severe frailty had a median 30-day mortality of 50%, with a six-month mortality rate of 73% when acuity was high.
2. For COVID-19, the case fatality rate for community-dwelling adults age 70 to 79 years is 8%; for those over 85, it is 15%
3. Older adults in a long-term care facility are at high risk of contracting COVID-19 and suffering from complications, including death

The outbreak of COVID-19 in a long-term care facility in Kirkland, Washington resulted in 101 of the 130 residents contracting the virus within 11 days. As of March 18th, 55 % of those residents were hospitalized and 34% had died. (New England Journal of Medicine, March 27, 2020)

STEP 6: Set time for a conversation

Goals of care conversations take time for the family to understand the issues and ask questions.

Okay, you're ready!



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HAVING THE CONVERSATION

You may already have an approach to advance care planning. If you're not sure where to start or want some guidance, consider completing the following tasks.

Not sure how to say it? Key phrases and wording for each step are included on the printable worksheet to support your conversation.

TASK 1: Introduce the purpose of the conversation and why It's important to plan ahead

Acknowledge the emotional nature of the situation and the conversation you'd like to have. Frame the discussion as an opportunity to ensure the resident receives the care that they will need and benefit from.

TASK 2: Assess the SDM's understanding of the resident's frailty and cognitive status and how frailty affects response to COVID-19

Describe the frailty cycle, including the concept of incomplete recovery and what this may mean for function/quality of life after infection.

Ensure that the SDM understands the resident's frailty stage (and dementia stage where applicable), as well as what to expect in the future.

TASK 3: Introduce the applicable options for the resident's situation

Present only those options that fit the resident's unique circumstances and align with current, facility-specific policies. Treatment options include:

1. Escalate care: Active care in the long-term care facility with transfer to hospital for further management, if necessary
2. Treat in place - no escalation: Treat in the long-term care facility but without transfer to hospital. If deterioration occurs, provide comfort care.
3. Comfort care only.

TASK 4: Provide your recommendation

Many SDMs describe feeling isolated and burdened when asked to choose between options that may seem equally appropriate. By providing a recommendation, you are not closing the door to further discussion, but signaling that some options may be more appropriate than others. This approach can ease SDM suffering.

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Describe the following:

- a) Treatment can involve suffering, which can be a significant burden. Suffering is not only related to pain but time away from the LTC facility and staff, delirium, agitation, and new routines in care.
- b) Intubation and aggressive medical care do not benefit most older adults with dementia or advanced frailty.
 - For example, the survival rate after CPR in the long-term care facility is generally less than 3%. In a recent study, survival to hospital discharge for those with moderate to severe frailty was only 1.8% (Wharton C. *Resuscitation*. October 2019; 143: 208–211).
 - Therefore, physicians should recommend against CPR and have further discussion with the SDM if they disagree
 - **Community-dwelling patients** with COVID-19 who require intubation, are on a ventilator for an average of three weeks. Long intubations are particularly detrimental in frailty and will be associated with significant loss of muscle mass and other complications.
- c) Survival means that a person will live to progress through more advanced stages of other chronic health issues, including dementia
- d) Depending on the resident's quality of life, the severity of infection, and resident and family values, Covid-19 infection with advanced frailty may provide an opportunity for a comfortable death

TASK 5: Check for understanding

Ask the SDM to describe what they've heard from you. This can identify important gaps in their understanding or interpretation of what you've shared.

AFTER THE CONVERSATION

Consider whether you feel there is alignment between your understanding and expectations and those of the SDM.

Do the goals of care fit with the prognosis? If not, you could:

- Revisit the conversation again if COVID-19 develops
- Ask the SDM to involve others in the circle of care who may help the SDM better understand the issues for the next discussion
- Contact a colleague for a second opinion or support
- See Geriatrics and Palliative Care Specialist contact information sheet for local expert resources

These are difficult times and difficult conversations.

Thank you for taking the time to review this document and considering the use of the worksheet.

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ADDITIONAL RESOURCES

NSHA Library Guides:

- Palliative Care: <https://library.nshealth.ca/PalliativeCare>
- Frailty: <https://library.nshealth.ca/Frailty>

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Discussing Goals of Care – A Worksheet for Health Care Professionals in Long-Term Care

This resource was adapted with kind the permission of Paige Moorhouse and Laurie Malley who developed it using the Palliative and Therapeutic Harmonization (PATH) approach to care. For more information on PATH go to: pathclinic.ca

This worksheet is intended to provide a structured process (including suggested cues and phraseology) that may help care providers discuss goals of care with LTC residents/SDMs in preparation for the COVID-19 pandemic. It is intended for use as a resource and not part of the medical record.

Please also refer to the following related resources: **GOALS OF CARE DISCUSSIONS FOR LTC RESIDENTS: A RESOURCE FOR PROVIDERS IN LONG-TERM CARE** and the **PLANNING AHEAD FOR COVID-19: A RESOURCE FOR FAMILIES OF LONG-TERM CARE RESIDENTS**.

CHECKLIST FOR PREPARATION:

- I've familiarized myself with the treatments currently available at this nursing home and current policies regarding hospital transfer for LTC residents with COVID-19
- I've determined whether the resident has capacity to make complex medical decisions. If not, I have involved the resident' substitute decision maker (SDM)
- I've determined the resident's baseline frailty level (check all that apply):

Stage (Clinical Frailty Score)	What day-to-day function looks like? If descriptors in more than one level apply, the final frailty score is the more severe level
Moderate (6)	<input type="checkbox"/> Needs reminders to change clothes or bathe but once reminded, can do the steps independently <input type="checkbox"/> Needs hands on help with stairs or getting into the tub
Severe (7)	<input type="checkbox"/> Needs the hands-on help of staff for bathing and dressing <input type="checkbox"/> Needs the hands-on help from staff for walking or /transferring
Very Severe (8)	<input type="checkbox"/> Completely dependent on staff for all care <input type="checkbox"/> Mostly confined to bed or chair

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- I've determined the resident's current dementia stage because this will help inform prognosis (circle one):

Dementia Stage	Function	Example of cognitive testing
No dementia	Would be able to do banking and manage medications without errors on their own if needed	Remembers details of recent and current events
Mild	Needs help with IADLs (e.g. banking) due to cognitive impairment	Trouble remembering recent news events (for example, is unaware of the pandemic, can't name COVID-19 or can't describe medical conditions)
Moderate	Needs reminders to change clothes or bathe but once reminded, can do the steps independently Note: If this resident has experienced behavioral symptoms they are at least in the moderate stage. Read the description of severe stage below to see if it applies.	Trouble naming the Canadian Prime Minister or US President
Severe	Needs hands-on help from staff for bathing and dressing due to cognitive impairment. If staff are already providing this help for physical reasons, they might not be aware that cognition is also limiting ability to complete the task.	Trouble naming first degree relatives
Very Severe	Unable to walk due to dementia	Speaks less than 10 words



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- I've considered individual circumstances regarding frailty stage, dementia/comorbidities. Check all that apply:
 - Frailty or dementia stage is MODERATE:** Case fatality rate from COVID-19 is much higher than in the general population. Active treatment may be appropriate but survival will likely be associated with more functional dependence, worse cognition, or deterioration in quality of life
 - Frailty or dementia stage is SEVERE:** This resident is in the last chapter of life. Patients with severe frailty do not respond well to intensive interventions such as intubation or CPR. A comfort care approach to COVID-19 may be appropriate.
 - Frailty or dementia stage is VERY SEVERE:** This resident is at the end of life. A comfort care approach to COVID-19 is most appropriate.
 - Successful active treatment (i.e. survival) may increase the chances that the patient will live to experience more advanced stages (and associated symptom burden) of this patient's other conditions, such as (check all that apply):
 - CHF
 - COPD
 - Dementia
 - Behavioral symptoms of dementia
 - Other (e.g., cardiac or pulmonary disease, such as interstitial fibrosis or valvular heart disease)

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DURING THE CONVERSATION:

Your clinical judgement and experience are critical. Below is a guide outlining specific areas of focus for these discussions and phrases/wording that may further support the conversation.

- ☐ I've highlighted the phrases below I might like to use during the conversation

TASK	DISCUSSION GUIDE
Introduction	<p>Thanks for taking the time for this important conversation.</p> <p>These are difficult times and I'm sure you must be feeling worried about how the pandemic will affect your [RELATION].</p> <p>We're working hard to do everything we can to prevent COVID-19 from spreading, and part of this work is planning ahead.</p> <p>I'd like to discuss a plan for what we'll do if your [RELATION] develops COVID-19 infection.</p> <p>I know you already have a care plan that says ____ but now is a good time to update this in light of the pandemic.</p>
Assess SDM understanding	<p>Tell me a bit about what you understand about how COVID-19 might affect your [RELATION].</p> <p>Tell me a bit about how you're feeling about your role as the decision maker.</p>
Lay the groundwork	<p>We want to do everything we can to support your [RELATION]. Part of that support is ensuring that we carefully select treatments that are most appropriate for this stage of life.</p>
Describe resident's frailty/dementia and what could be expected from survival of COVID-19	<p>To address dementia <i>(if applicable)</i>:</p> <ul style="list-style-type: none"> ● You may be aware that your [RELATION] has dementia. Dementia is when problems with memory and thinking interfere with day to day life. Although we often think of dementia as affecting memory, in reality, dementia is a key factor in how COVID-19 will affect your [RELATION]'s future health. ● Dementia helps us predict how a person will fare if they develop COVID-19 ● Dementia is progressive. Right now, your [RELATION] is in the ____ stage. Recovery from COVID-19 may involve worsening of memory and progressing to the next stage, which is the ____ stage, where people have trouble with

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TASK	DISCUSSION GUIDE
	<p>[describe function in next stage].</p> <p>To address frailty:</p> <ul style="list-style-type: none"> • Your [RELATION] is MODERATELY frail. Treating COVID-19 with active measures may support your [RELATION]’s recovery. We can discuss the specifics of what interventions will be helpful/available and where care will be delivered. It’s important to remember that treating COVID-19 won’t fix the other longstanding health issues that your [RELATION] has. It’s also important to keep in mind that if your [RELATION] recovers, their day to day abilities and quality of life are not as good as they are now. • Your [RELATION] is SEVERELY frail and in the last chapter of life. A comfort approach to COVID-19 may be most appropriate. • Your [RELATION] is VERY SEVERELY frail and at the end of life. A comfort approach to COVID-19 is most appropriate. <p>By knowing this, we want to ensure that the treatments we choose will help your [RELATION] at this time.</p>
<p>Introduce the options (they may vary by jurisdiction and over time)</p>	<p>Would you like me to start by describing all the options, or would you like me to start with my recommendation for how to approach COVID-19 in your [RELATION]? (If latter, skip to <i>Provide Recommendations</i> section below)</p> <p>There is no cure for COVID-19 but there are [two/three] main options (only present the options if they are consistent with local policies as the situation evolves)</p> <p>Regardless of the option chosen, physical symptoms such as breathlessness and fever can be managed with medication and other means such as oxygen.</p> <p>OPTION #1: Escalate care:</p> <ul style="list-style-type: none"> • We would start treatment for COVID-19 here. For infections too severe to treat in the nursing home, we would send your [RELATION] to hospital. The kinds of treatments we would use could include oxygen, and intravenous fluids. • Some severe cases of COVID-19 are being managed in ICUs with breathing machines. Frail residents from nursing homes do not do well in intensive care,

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TASK	DISCUSSION GUIDE
	<p>especially when a breathing machine is needed.</p> <ul style="list-style-type: none"> • <i>If applicable:</i> I would not recommend intensive care for your [RELATION] as they would not be expected to survive. <p>OPTION #2: Treat in place--No escalation:</p> <ul style="list-style-type: none"> • We will try to treat infection with the measures we have in the nursing home; however, if the infection progresses, we will change the focus to comfort and allow a comfortable death. <p>OPTION #3: Comfort care only:</p> <ul style="list-style-type: none"> • We will manage symptoms in the nursing home with a focus on maintaining comfort using medications to help with breathlessness, anxiety, pain and other symptoms to allow for a comfortable death. <p>(In the event that your [RELATION] is dying, we will make every effort to allow visitation if possible.)</p>
Provide recommendations	<p>I've carefully considered all of your [RELATION]'s individual health circumstances. I would recommend that if your [RELATION] develops COVID-19.</p> <ul style="list-style-type: none"> • Escalate care: We try to help your [RELATION] survive this infection including transfer to hospital for further treatment if needed. In this case, the kinds of treatment that will be offered might include: <ul style="list-style-type: none"> ○ Fluids ○ Oxygen ○ ICU [discussion should only occur if within policy/goals of care]. Given that nursing home patients do poorly with ICU care, I would recommend against transfer to the ICU. Similarly, I would not recommend using a breathing machine, known as a ventilator. ○ The survival rate with CPR (resuscitation) in nursing home patients is about 3%. I would not recommend CPR in the setting of COVID-19 because we cannot treat the underlying issue. • Treat in place--no escalation: We try to treat infection with the therapies that are available in the nursing home but if the infection progresses, we will switch our focus to comfort. By staying in the nursing home, your [RELATION] won't have to

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TASK	DISCUSSION GUIDE
	<p>experience the difficulties that are associated with transfer to hospital or being in an unfamiliar environment.</p> <ul style="list-style-type: none"> • Comfort care only: We focus on supporting a comfortable end of life and death in the nursing home. This might include using medications to help with any breathlessness, pain, or anxiety and providing appropriate care that will allow a comfortable death. <p>In the event that your [RELATION] is dying, we will make every effort to allow visitation if possible.</p>
Check for understanding	<p>I recognize this is a lot of information to take in. These are difficult times and tough decisions. Do you have any questions?</p> <p>Does what I'm saying fit with what you were thinking?</p> <p>Are there other family members you'll be talking about this with? If so, what will you tell them?</p>
Provide reassurance	<p>We will continue to work with you to provide a supportive care environment for you and your [RELATION].</p> <p>Please keep in touch with us if you have questions or concerns.</p>

CONVERSATION CHALLENGES

I'm talking with the SDM and the conversation is not going well! Possible conversation challenges you may encounter along with suggested responses are available below (Sourced with permission to use from: <https://www.vitaltalk.org/guides/covid-19-communication-skills/>). These helpful tips (outlined below) are from clinicians in Seattle who've been there. Of course, these questions also come up outside of COVID-19, and responses reflect best practices for supporting family members of those who are severely or very severely frail.

IF THEY SAY:	WHAT YOU SAY AND WHY:
<i>I want everything possible. I want them to live</i>	Of course you do! This is a tough situation. Could we step back for a moment so I can learn more about you and your [RELATION]? <i>What do I need to know about you to do a better job taking care of them?</i>



Caring for LTC Residents During COVID-19 Pandemic: A Guide to Managing Symptoms and End-of-Life Care

IF THEY SAY:	WHAT YOU SAY AND WHY:
<i>I'm not sure what my [RELATION] would have wanted. We never spoke about it.</i>	You know, many people find themselves in the same boat. Who could have imagined this tough situation? To be honest, given his overall frailty now, if he became so ill people were talking about CPR or breathing machines, he would not make it. The odds are just against him. <i>My recommendation is that we accept that he will not live much longer and allow him to pass on peacefully.</i> I know that is hard to hear. What do you think?
<i>Why isn't the ICU an option?</i>	<i>This is an extraordinary time. We are trying to use resources in a way that is fair for everyone.</i> Your [RELATION]'s situation does not meet the criteria for the ICU today. I wish things were different.
<i>This approach sounds age-ist</i>	No. <i>We are using guidelines that were developed by people in this community and other communities who have been through COVID-19 to prepare for an event like this</i> —clinicians, policymakers, and regular people— <i>so that no one is singled out.</i> These guidelines have been developed over years--they weren't done yesterday. I know it is hard to hear this.
<i>This sounds like rationing</i>	What we are doing is trying to spread out our resources in the best way possible. <i>If this were a year ago, we might be making a different decision. This is an extraordinary time. I wish I had more resources.</i>
<i>I don't know how to tell this resident's SDM we can't [transfer to hospital/ICU] and that the resident is going to die</i>	<i>Remember what you can do:</i> you can hear what [RELATION] is concerned about, you can explain what's happening, you can help your [RELATION] prepare, and you can be present. These are gifts.
<i>Do I need to start preparing for my [RELATION] to die?</i>	I am hoping that is not the case but I worry that time could indeed be short. What are you thinking about this happening?
<i>I need some hope</i>	Tell me about the things you are hoping for. I want to understand more from you about this. Hope is a skill. Having accurate information will help you frame hope in a way that is less likely to end in disappointment.

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AFTER THE CONVERSATION:

- I believe the plan for how we will manage COVID-19 infection in this resident is appropriate.
- I'm concerned that the plan for how we will manage COVID-19 infection in this resident **does not match** their prognosis.
 - I'll revisit the conversation again if COVID-19 develops
 - I'll ask the SDM to involve others in the circle of care who may assist the SDM in understanding the issues for the next discussion
 - I'll contact colleagues for a second opinion or support (consider calling the PATH clinic through their website pathclinic.ca to request a call)
- I've documented the plan in the resident's chart

NSHA LIBRARY GUIDE RESOURCES

- Palliative Care: <https://library.nshealth.ca/PalliativeCare>
- Frailty: <https://library.nshealth.ca/Frailty>

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Additional Resources for Management of LTC Residents COVID-19

Goals of Care Discussions/Advance Care Planning:

- 1) www.vitaltalk.org/guides/covid-19-communication-skills/
 - COVID-Ready Communication Skills. A Playbook of VitalTalk Tips.
 - Includes suggestions for responding to patients' and families' questions and concerns on a wide variety of COVID-19 related issues.
- 2) www.advancecareplanning.ca
 - Canadian Hospice Palliative Care Association's "Speak Up" campaign
 - Resources for patients/families and health care providers for advanced care planning

Geriatric Medicine Resources:

- 1) <https://canadiangeriatrics.ca/covid-19-resources/>
 - Canadian Geriatrics Society website, including a collection of a variety of resources pertinent to managing the care of older individuals in the context of COVID-19
- 2) <https://www.rgptoronto.ca/resources/covid-19/>
 - Regional Geriatric Program of Toronto's COVID-19 Resource page

Symptom Management and Assessment:

- 1) http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Final+Days/When+Death+is+Near.aspx
 - Canadian Virtual Hospice article "When Death is Near"
 - Covers a broad range of physical, emotional and practical changes and challenges that may be encountered as death approaches
- 2) http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/What+Is+Palliative+Care+10+Myths+about+Palliative+Care.aspx
 - Virtual Hospice – 10 Myths about Palliative Care
 - Quick reference for answers to common misconceptions about palliative care
- 3) <https://www.pallium.ca/course/covid-19-response-free-online-modules/>
 - Pallium Canada's LEAP (Learning Essential Approaches to Palliative Care) online modules
 - Pallium is exceptionally making LEAP modules pertinent to managing individuals dying from an acute respiratory illness available free of charge. The LEAP course one of the most widely recognized and accessed primary palliative care education courses in the country
- 4) <https://www.pallium.ca/fr/course/en-reaction-a-la-covid-19-modules-en-ligne-gratuits/>
 - LEAP free online modules in French

General COVID-19 information:

- 5) www.gnb.ca/coronavirus
 - Office of the Chief Medical Officer of Health (Public Health) of New Brunswick
 - Information about screening, self-isolation, prevention, and up to date epidemiologic information
- 6) <http://skyline/Physicians/Pages/COVID-19-Memos-and-Information.aspx>
 - Horizon Health Network's Skyline COVID-19 Physician page
 - Information, memos, guidelines and links
- 7) <https://app.spectrum.md/en/clients/230-horizon-health-network>
 - NB and Horizon anti-infective stewardship committees' Spectrum app
 - includes guidelines for management of COVID-19