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 asked the SDM to view the YouTube video to prepare them for our conversation
- ❑ 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)	❑ 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
Severe (7)	❑ Needs the hands-on help of staff for bathing and dressing ❑ Needs the hands-on help from staff for walking or /transferring
Very Severe (8)	❑ Completely dependent on staff for all care ❑ Mostly confined to bed or chair

❑ 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

❑ 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)

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	Thanks for taking the time for this important conversation. These are difficult times and I'm sure you must be feeling worried about how the pandemic will affect your [RELATION]. We're working hard to do everything we can to prevent COVID-19 from spreading, and part of this work is planning ahead. I'd like to discuss a plan for what we'll do if your [RELATION] develops COVID-19 infection. I know you already have a care plan that says _____ but now is a good time to update this in light of the pandemic.
Assess SDM understanding	Tell me a bit about what you understand about how COVID-19 might affect your [RELATION]. Tell me a bit about how you're feeling about your role as the decision maker.
Lay the groundwork	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.
Describe resident's frailty/dementia and what could be expected from survival of COVID-19	**To address dementia** *(if applicable)*: • 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-19will affect your [RELATION]'s future health. • Dementia helps us predict how a person will fare if they develop COVID-19

TASK	DISCUSSION GUIDE
	• 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 [describe function in next stage]. **To address frailty:** • 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. By knowing this, we want to ensure that the treatments we choose will help your [RELATION] at this time.
Introduce the options (they may vary by jurisdiction and over time)	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 *Provide Recommendations* section below) 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): OPTION #1: **Escalate care**: • 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.

TASK	DISCUSSION GUIDE
	• 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, especially when a breathing machine is needed. • *If applicable*: I would not recommend intensive care for your [RELATION] as they would not be expected to survive. OPTION #2: **Treat in place--No escalation**: • 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. OPTION #3: **Comfort care only:** • 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. In the event that your [RELATION] is dying, we will make every effort to allow visitation if possible.

Provide recommendations	I've carefully considered all of your [RELATION]'s individual health circumstances. I would recommend that if your [RELATION] develops COVID-19.
	
	• **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:
	  ○ 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 intubation.
	  ○ As you know 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.

TASK	DISCUSSION GUIDE
	• **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 experience the difficulties that are associated with transfer to hospital or being in an unfamiliar environment. • **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. In the event that your [RELATION] is dying, we will make every effort to allow visitation if possible.
Check for understanding	I recognize this is a lot of information to take in. These are difficult times and tough decisions. Do you have any questions? Does what I'm saying fit with what you were thinking? Are there other family members you'll be talking about this with? If so, what will you tell them?
Provide reassurance	We will continue to work with you to provide a supportive care environment for you and your [RELATION]. Please keep in touch with us if you have questions or concerns.

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 want everything possible. I want them to live	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]? ***What do I need to know about you to do a better job taking care of them?***
I'm not sure what my [RELATION] would have wanted. We never spoke about it.	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. ***My recommendation is that we accept that he will not live much longer and allow him to pass on peacefully.*** I know that is hard to hear. What do you think?
Why isn't the ICU an option?	***This is an extraordinary time. We are trying to use resources in a way that is fair for everyone.*** Your [RELATION]'s situation does not meet the criteria for the ICU today. I wish things were different.
This approach sounds age-ist	No. ***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***—clinicians, policymakers, and regular people—***so that no one is singled out***. These guidelines have been developed over years--they weren't done yesterday. I know it is hard to hear this.
This sounds like rationing	What we are doing is trying to spread out our resources in the best way possible. ***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 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	***Remember what you can do***: 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.
Do I need to start	I am hoping that is not the case but I worry that time could indeed be short. **What**

IF THEY SAY:	WHAT YOU SAY AND WHY:
preparing for my [RELATION] to die?	**are you thinking about this happening?**
I need some hope	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

Have another helpful phrase? Email it to info@pathclinic.ca and we'll add it to future versions of the document

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