COVID-19 GOALS OF CARE DISCUSSIONS FOR LONG TERM CARE RESIDENTS: A RESOURCE FOR PROVIDERS IN LTC

THIS IS A CHALLENGING TIME: PREPARATION WILL HELP

During the coronavirus (COVID-19) pandemic, frail nursing home residents are at risk for severe and fatal disease. This document outlines the specific impact of COVID-19 for older nursing home 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.***

While some of this work may not have a physician fee code, advance-care planning remains a critical part of caring for nursing home 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.

STEP 2: Identify the substitute decision-maker (SDM)

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

This resource was developed by the Palliative and Therapeutic Harmonization Program in collaboration with the NSHA-Central Zone Frailty Strategy. For more information on PATH go to: pathclinic.ca; Frailty Strategy e-mail: frailtystrategy@nshealth.ca

resident and the SDM. Therefore, offer the SDM the opportunity to speak privately.
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.

Encourage the SDM to review the 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

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.

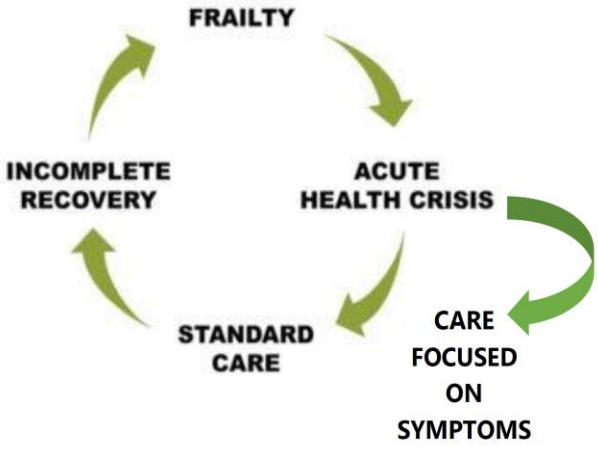
Stage (Clinical Frailty Scale)	**What function looks like**	**What cognition may look like** (if dementia is present)
Moderate (6)	Any of the following: • Needs reminders to change clothes or bathe but once reminded, can do the steps independently • Needs hands-on help with stairs or getting into the tub	Has difficulty naming the Canadian Prime Minister or United States President
Severe (7)	Any of the following: • 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: • 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 nursing home 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 nursing home. 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.



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 nursing homes are at high risk of contracting COVID-19 and suffering from complications, including death

The outbreak of COVID-19 in the Life Care Centre in Kirkland, Washington resulted in 129 cases of the virus within 11 days. As of March 18th, 27 % of residents who contracted COVID-19 died. (Centre for Disease Control Morbidity and Mortality Weekly Report, March 18, 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!

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 nursing home with transfer to hospital for further management, if necessary
2. Treat in place - no escalation: Treat in the nursing home 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.

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 nursing home 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
- If you're located within Nova Scotia, consider calling the PATH clinic at 902-473-3888 for more guidance or support

These are difficult times and difficult conversations.
Thank you for taking the time to review this document and considering the use of the worksheet.

ADDITIONAL RESOURCES

NSHA Library Guides:

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

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