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 truthful and practical information, we can 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 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 developed COVID-19 have died.
(Centre for Disease Control Morbidity and Mortality Weekly Report, March 18, 2020)

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

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.
FRAILTY

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

FRAILTY 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:
- Negative effects on 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

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—around 30% in the Washington state nursing home, with other estimates being higher
PLANNING AHEAD FOR COVID-19
A RESOURCE FOR FAMILIES OF LONG-TERM CARE RESIDENTS

- 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 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:

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<th>OPTION</th>
<th>WHAT IS INVOLVED</th>
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<td>1. ESCALATE CARE</td>
<td>The goal is to lengthen life and could involve one or more of the following:</td>
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<td>- Transfer to hospital</td>
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<td>- Oxygen</td>
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<td>- Intravenous fluids</td>
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<td>- Use of ventilator/breathing machine</td>
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<td>Some treatments may be available in the nursing home while others may only be available in hospital.</td>
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<td>Once a breathing machine is needed, the outcome with frailty is generally very poor. Treatment will likely cause more suffering than benefit.</td>
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<td>It is important to remember that available treatments may vary by area and over time as the pandemic evolves.</td>
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Therefore, the ability to hospitalize and/or use a breathing machine will depend on whether the service is available.

| 2. TREAT IN PLACE – NO ESCALATION | This care option involves:  
- 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, rather than transferring to hospital. |

| 3. COMFORT CARE ONLY | This care option includes:  
- 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  
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. |

**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](https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1645.pdf)  
Stages of Frailty:  
[https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1644.pdf](https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1644.pdf)