

CONSIDERATIONS TO MAKE BEFORE MOVING A PERSON LIVING WITH DEMENTIA OUT OF LONG TERM CARE

COVID-19 poses a risk for our elderly and family members both in the community and in long-term care. As a care partner, you may be especially worried about the risk to your family member or friend in their long-term care home should COVID-19 cases appear there. This may lead you to consider removing them from long-term care, either permanently or temporarily.

This is a challenging decision where many factors need to be considered. It is important to ask questions, consider facts and understand what challenges you may face should you move the person living with dementia back to a home environment.

Below you will find a list of important questions to think about. This list does not include all possible questions but provides several important questions to help you make the decision you are most comfortable with and that best fits your individual circumstances.

Where possible, you are encouraged to include the person living with dementia in the decision-making.

Consider the following:

Notes:

If required, are you prepared to self-isolate for 14 days along with the person living with dementia when they leave long-term care?

Can you gather all the supplies you will need (such as groceries, medications, etc.) for this timeframe?

Tip: This means that you will not be able to leave your home for 14 days for any reason, aside from a medical emergency.

Will the long-term care home doctor continue to provide care and for how long?

If the person living with dementia leaves long-term care, will they have access to their long-term care doctor for any medical concerns?

Will the long-term care doctor continue to support prescription (medication) refills?

Consider the following:**Notes:**

What will you do if the care partner or person living with dementia becomes sick?

What if you become unwell from COVID-19 or another medical condition? What is the back-up plan?

If you need hospitalization, who will care for the person living with dementia?

What will you do if the person living with dementia becomes unwell or has worsening medical condition(s)?

Can you monitor the person living with dementia's medical condition(s)?

Will the long-term care bed be held and for how long?

Will the person living with dementia be formally discharged and required to reapply through the LHIN, or is it possible to have a Leave of Absence?

If the person living with dementia has stayed away from the long-term care home for a length of time and the bed can no longer be held, how soon will the person living with dementia be able to return to a long-term care home?

What is the process to return to the long-term care home? For example, do you have to reapply for a long-term care home bed?

Does the process to return to the long-term care home look different if returning in a crisis (such as care partner illness) versus returning after the pandemic?

Will the person living with dementia return to the same long-term care home or could it be a different long-term care home?

Consider the following:

Notes:

Will the person living with dementia resist returning to long-term care home once they have been home/another location not in long-term care?

At the time of return to long-term care, will the person living with dementia be required to self-isolate for 14 days or follow any new rules provided by the government?

Tip: As government regulations may change during this pandemic, it is important to talk to the Administrator or LHIN Care Coordinator of the long-term care home directly.

What are the risks for contracting COVID-19 at home?

If the person living with dementia is leaving a long-term care home with an COVID-19 outbreak, could the person living with dementia have the virus but be symptom free?

What self-isolation practices will be expected of you with both people outside of your home and with those inside your home?

Is there a risk that the person living with dementia will spread the virus to someone in your home?

Is there anyone in your home that is immunocompromised and at greater risk of more severe COVID-19 symptoms if exposed?

What risks are there for care providers in the home or care providers coming to the home, infecting the person living with dementia?

Consider the following:

Notes:

What behaviours does the person living with dementia have that may be difficult to manage at home?

Is the person living with dementia someone who shows responsive behaviours such as striking out, yelling or increased anxiety?
Can you handle this alone?

Have staff at the long-term care home told you that the person living with dementia has shown responsive behaviours while in their care (even if they are not demonstrating the behaviours now)?

Is it possible that the person living with dementia will wander (day or at night) or try to exit the home?

Will the person living with dementia recognize who you are?

Will the person living with dementia accept, or resist, care from you?

Tip: Please note that when a person living with dementia has a change in their routine, such as moving from one location to another, there is an increased risk that they will show signs of fear, anxiety, or anger. These feelings may result in responsive behaviours like those mentioned above.

What are the care needs of the person living with dementia?

Can the person living with dementia walk safely around the home?

How will the person living with dementia manage stairs if this is necessary? Are there railings?

Consider the following:**Notes:**

If the person living with dementia needs a wheelchair, can the wheelchair be managed around the home?

Can you manage transfers of the person living with dementia to/from chair, bed, or toilet?

Are you and the person living with dementia comfortable with you providing personal care, such as bathing or toileting? Please remember that comfort levels may have changed since the person lived in their own home.

Can you obtain any equipment that is needed to provide care (e.g., hospital bed, commode, bathroom equipment or safety grab bars)?

How much help does the person living with dementia need for self-care: dressing, toileting, grooming or bathing? Can you manage this care alone?

Is the person living with dementia frequently incontinent? If so, can you manage this care?

Does the person living with dementia have oxygen needs? Can you arrange for this service at home and at what cost?

Does the person living with dementia have difficulties eating or swallowing?

Does the person living with dementia have skin care issues? Can you manage this?

Will the person living with dementia sleep through the night? How will your sleep be impacted?

Can you keep up the level of care needed for weeks and maybe months?

Can you manage at home with the person living with dementia 24 hours per day, 7 days per week?

Consider the following:

Notes:

What supports will you have?

Do you provide care to others within your home, such as children, people with special needs, etc.?

Can you manage the support of all individuals under your care while maintaining your own health and well being?

What supports do you have in the home?

Are there any supports through the Home Care program to help you?

Are family members willing or able to provide support? If yes, will they isolate in the home?

If you need to depend on help from outside the home, how available are these supports through other family members, friends, or private hire?

How will you obtain groceries, medications or leave home for essential appointments?

Please note that there may be limits to the availability of Personal Support Workers. It will be helpful to ask the LHIN Care Coordinator about available supports prior to making any decisions.

Consider the following:

Notes:

What were the reasons for the person living with dementia moving to the long-term care home?

What stresses were you experiencing physically and emotionally when you were supporting the person living with dementia at home (your home or that of the person living with dementia)?

Can you manage these stresses now?

Has your medical health changed (new or worsened medical conditions) since the person living with dementia was admitted to long-term care home? Do you think that this will reduce your ability to provide the care needed by the person living with dementia?

Is it possible that your medical conditions could become worse?

Can you financially afford to provide care during these times of employment uncertainty and unemployment?

Are there any risks to the level of your income that will impact your ability to provide care?

Who do you need to talk to for information when considering this decision?

Administrator and Nursing at long-term care home

Medical doctor at long-term care home
LHIN Care Coordinator

Other family members

Your own family physician

What are the next steps?

After reviewing the questions above, you may have unanswered questions for others to help you make the choice that you are most comfortable with. You may find it helpful to list these questions below.

Questions:

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.

For more information and support please contact your local Alzheimer Society.

References:

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Also adapted and used with permission, Alzheimer Society of Grey-Bruce (2020).