

## Considering the move to a Long-Term Care home

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This information is for you if you are caring for someone with Alzheimer's disease or other dementias and you are considering moving them to a long-term care home. From talking to families, we know that considering moving the person you care for to a long-term care home may be one of the most difficult decisions you will ever have to make. This information covers things to think about and hands-on tips for considering a move for a person with dementia.

Alzheimer's disease and other dementias are progressive, degenerative diseases, which means that the person's symptoms will gradually get worse. There may come a time when you can no longer provide care in your own home.

As a caregiver you should not consider a move as a failure or selfishness. Recognize that it is a very common step in the overall progression of the disease. In fact, 57% of seniors living in a long-term care home have a diagnosis of Alzheimer's disease or other dementia, and for many, this will be their final home as 70% of all people with dementia die in nursing homes.

As you consider a move, you may experience a broad range of emotions. For example, you may feel guilt, loss, sadness, anger, shame, and resentment, as well as a sense of failure. You may also feel relieved that you now share the responsibility for providing care with others. You may even have second thoughts about your decision.

It is important to understand that these are all normal reactions and that numerous people, like the staff at your local Alzheimer Society, are available to help you through the process.



### A note about the terms we use:

- "Family" and "Caregiver" refer to anyone involved in caring for or providing support to someone with dementia.
- "Dementia" refers to Alzheimer's disease and other dementias.
- "Long-term care home" and "home" refer to a "nursing home". The terms for nursing home vary across Canada; we use "long-term care home" or "home" for easier reading.

## Reasons for considering a move

There are no rules guiding when you will come to the conclusion that a move is necessary.

You may consider a move for a variety of reasons:

- The condition of the person with dementia has worsened. They may have been in hospital and their needs are becoming more complex so they require more help on a day-to-day basis.
- You are concerned about the person's safety.
- You no longer feel able to provide the full time care that the person requires to enjoy the highest possible quality of life.
- Your health and abilities have changed or you are exhausted.

## A Balancing Act

When considering how best to meet the needs of the person with dementia, you need to remember to balance their needs with your own well-being. Use the following checklist to help assess how stress may be affecting your life.

*"Everyone said it's time for your mom to move to a long-term care home. You've done enough, it's taking a toll. I had a lot of guilt. You almost feel like a failure, but you're trying to do the impossible." – Caregiver in Nova Scotia, Canada*



## Caregiver Stress Assessment Checklist

Answer the following questions by selecting "Never," "Sometimes," or "Often."

Questions	Never	Sometimes	Often
Do you have difficulty falling asleep?			
Do you wake up in the middle of the night?			
Do you have stressful dreams?			
Have you gained or lost weight recently without intending to?			
Do you get sick more often than you used to (e.g., frequent colds or flu)?			
Have you developed chronic health problems (e.g., backache, headaches, high blood pressure)?			
Do minor upsets make you cry, angry or unusually agitated?			
Do you find it difficult to control your temper?			
Do you feel pressure to hold things together?			
Are you feeling hopeless about your situation?			
Have you given up hobbies or interests that you enjoy?			
Are you spending less time with others?			
Is caregiving affecting your career?			

*If you answered "sometimes" or "often" to many of these questions, you may need help balancing caring for the person with dementia and caring for your own well-being. No matter how close you are to the person, you may want to consider including others in the caregiving role. Caregiving involves a range of responsibilities and sharing these responsibilities will help you and the person with dementia have a better quality of life.*

## Finding the right long-term care home

To help make the best decision, familiarize yourself with the long-term care homes in your area and ask questions about the services, policies, and costs so you are ready to make a decision quickly when a room becomes available.

In addition, you may find it useful to bring along a friend or family member for input and support. It is also helpful to talk to residents and their family members. Some long-term care homes provide tours that are led by family volunteers giving you a chance to speak with other families of residents and ask questions.

Pay attention to your gut feelings; these are your instincts, which can be very helpful in determining if a home is appropriate for the person you are caring for.

When a room becomes available in a long-term care home that you have applied to, the home often requires that you decide quickly if you would like to take the room or not. There are stiff penalties if you decide not to take the room such as being put on the bottom of the waiting list.

## About waiting lists

Your position on the waiting list, wait times, and the number of available rooms vary from one home to another and are constantly changing. Room availability is based on priority needs such as the person with dementia's condition, how much support the person currently has, and your condition as the caregiver.

If you urgently need to relocate the person with dementia to a home, a room may become available that is not your first choice. In this case, you can stay on the waiting list of the home that is your first choice and transfer the person with dementia as soon as room becomes available there.

However, once the person moves into a home, it is important to weigh the advantages and disadvantages of another move for both the person and yourself. If you have any questions, contact your local community care office or the health care professional that you are working with.

## Your homework

To help find the right long-term care home, follow these tips:

- Consider what your priorities and expectations are in a long-term care home. It is important to know that there are differences between private and publicly funded homes. Sometimes you don't get what you pay for; a more expensive room does not necessarily mean that the person will get better care.
- Contact your local community health centres for information about the long-term care application process in your area. Some communities have a number of homes to choose from. Make a list of long-term care home options and then narrow the list down to ones you would like to visit.
- Visit each home on your list to see firsthand what each one has to offer. Bring your list of priorities, expectations, and any questions you may have to the visit so that you don't leave out anything important. Some long-term care homes allow the person with dementia to visit the home and become familiar with it by way of day programs or respite services.
- Even after an extensive search, you may not find everything you want in a single home. Try to be flexible and consider whether you could work with the staff to meet the needs of the person with dementia.

Use the following checklist to help make the best decision for the person with dementia.



## Long-term Care Home Checklist

Make a copy of this checklist to use as you research and visit each long-term care home.

Long-term care home name: \_\_\_\_\_

Private home       Publicly funded home

Visit date: \_\_\_\_\_

Things to check before visiting the home	Yes	No	Notes
There are specific units for people with dementia.			<ul style="list-style-type: none"> <li>How is the unit different from other areas of the home? Is it a secure, locked area?</li> </ul>
The person with dementia is able to live here throughout the course of the disease.			
The home tells me the cost of the room and whether there are additional costs for extra care as the disease progresses.			<ul style="list-style-type: none"> <li>How much does the room cost? If there are additional costs, how much are they?</li> </ul>
The home offers tours and I know how to book one.			
There is a waiting list.			<ul style="list-style-type: none"> <li>If so, approximately how long is it?</li> </ul>
There are rules about waiting lists (e.g., people in crisis situations are given priority).			
The home is accredited and inspected regularly.			<ul style="list-style-type: none"> <li>If inspectors made recommendations during the last inspection, ask for a copy of the report.</li> </ul>

Things to check while visiting the home	Yes	No	Notes
<b>Physical Setup</b>			
The location is convenient and easy for me to visit.			<ul style="list-style-type: none"> <li>How long is the commute? Is it accessible by public transit? Is there free parking?</li> </ul>
The home is clean and tidy without seeming institutional and sterile.			<ul style="list-style-type: none"> <li>Are there unpleasant odours?</li> </ul>

Things to check while visiting the home	Yes	No	Notes
<b>Physical Setup...cont'd</b>			
There are quiet areas for visitors to spend time with residents.			
Residents can walk safely and easily indoors and outdoors.			
The bathrooms are clean with safety devices like grab bars.			<ul style="list-style-type: none"> <li>Do they easily accommodate mobility aids like walkers?</li> </ul>
There are clear signs throughout the home to help residents get around the home (e.g., a picture of a toilet on the bathroom door).			
<b>Resident Care and Staff Training</b>			
There is consistent staff assigned to each resident so staff and residents can get to know each other.			<ul style="list-style-type: none"> <li>Is there a rotation of many staff assigned to each resident?</li> </ul>
All staff is trained to care for residents with dementia.			<ul style="list-style-type: none"> <li>How frequently does all staff attend refresher courses?</li> </ul>
I see staff talking to residents in a personable manner, clearly showing that they know each resident as a unique individual.			
I see staff trying to understand what residents are trying to communicate through their actions.			
There are regular care planning meetings that can include family members (e.g., a care plan is a standard document for each resident that includes everything about the resident's care).			<ul style="list-style-type: none"> <li>Can families request a care meeting? How?</li> </ul>
With consent, the home shares information about the resident readily and routinely with family members.			<ul style="list-style-type: none"> <li>How does the home share the information?</li> <li>If I have concerns, who is my main contact?</li> </ul>
There is a doctor on call.			<ul style="list-style-type: none"> <li>Can a resident keep their family doctor if they like?</li> <li>What are the pros and cons of this decision?</li> </ul>
The home has access to other services (e.g., opticians, dentists, physiotherapists, chiropodists (foot care), hairdresser).			<ul style="list-style-type: none"> <li>Are there costs for these services?</li> </ul>

Staff uses restraints (e.g., seatbelts in wheelchairs, bedrails, antipsychotic medications) and I can see a copy of the restraint policy.			<ul style="list-style-type: none"> <li>• If yes, when and why?</li> <li>• Is this something I am comfortable with?</li> </ul>
Medical emergencies are handled appropriately.			<ul style="list-style-type: none"> <li>• How are medical emergencies handled?</li> <li>• Under what circumstances are residents transferred to hospital?</li> </ul>
Staff is able to provide palliative care (to reduce distress and provide enhanced comfort, dignity and pain control at end-of-life stage).			
<b>Daily Life</b>			
Each resident has a flexible daily routine (e.g., home can accommodate a resident who is used to having breakfast at 11am).			
The menu is good in all important ways (e.g., varied, appealing, nutritious, and can accommodate special dietary needs).			
The home considers different cultural, religious, and spiritual needs.			<ul style="list-style-type: none"> <li>• Do I have specific cultural, religious, or spiritual issues to ask about?</li> </ul>
There are a variety of meaningful activities for groups and individuals.			<ul style="list-style-type: none"> <li>• What are they?</li> <li>• Are they available during evenings and weekends? Ask for a program schedule.</li> <li>• Is there a volunteer visiting program for additional one-on-one support?</li> </ul>
I see residents that are inactive (e.g., falling asleep in front of the television).			
The visitors' policy suits the needs of the person with dementia and my needs as a visitor.			<ul style="list-style-type: none"> <li>• What is the policy regarding visits?</li> <li>• What are the visiting hours?</li> <li>• Can a caregiver or friend sleep over to comfort and assist a sick resident?</li> </ul>
The home allows visitors to join the resident for meals.			<ul style="list-style-type: none"> <li>• Is there a cost?</li> </ul>

Your overall impression:

Rate the long-term care home on the following scale:

1      2      3      4      5      6      7      8      9      10

I would never consider moving  
the person with dementia  
to this home.

I would consider this  
long-term care home as  
one of the best options.

Comments:

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<sup>i</sup> Canadian Institute for Health Information, Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia, August 2010.

<sup>ii</sup> Mitchell S, Teno J, Miller S, Mor V: A national study of the location of death for older persons with dementia. JAGS 2005, 53:299-305

# Alzheimer Society



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