

Considering the move to a Long-Term Care home

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:

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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	Always
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.

contact your local community care office or the

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.			
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"> How much does the room cost? If there are additional costs, how much are they?
The home offers tours and I know how to book one.			
There is a waiting list.			<ul style="list-style-type: none"> If so, approximately how long is it?
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"> If inspectors made recommendations during the last inspection, ask for a copy of the report.

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

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"> • If yes, when and why? • Is this something I am comfortable with?
Medical emergencies are handled appropriately.			<ul style="list-style-type: none"> • How are medical emergencies handled? • Under what circumstances are residents transferred to hospital?
Staff is able to provide palliative care (to reduce distress and provide enhanced comfort, dignity and pain control at end-of-life stage).			
Daily Life			
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"> • Do I have specific cultural, religious, or spiritual issues to ask about?
There are a variety of meaningful activities for groups and individuals.			<ul style="list-style-type: none"> • What are they? • Are they available during evenings and weekends? Ask for a program schedule. • Is there a volunteer visiting program for additional one-on-one support?
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"> • What is the policy regarding visits? • What are the visiting hours? • Can a caregiver or friend sleep over to comfort and assist a sick resident?
The home allows visitors to join the resident for meals.			<ul style="list-style-type: none"> • Is there a cost?

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:

¹ Canadian Institute for Health Information, Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia, August 2010.

ⁱⁱ 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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Preparing for a move

This information is for you if you are caring for someone with Alzheimer's disease or other dementias and you are preparing to move them to a long-term care home. From talking to families, we know that 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 to help you better prepare for the move.

The wait for a room in a long-term care home may be long, but the move is often sudden. If a room becomes available, it is common for the home to require an immediate commitment to take the room, often with a moving date within the next couple of days.

Many family members find that they do not have enough time to organize the logistics of the move, such as visiting the home before the move, filling out the required paperwork, packing belongings, arranging for movers, and preparing the person with dementia for the move.

You can make the move easier for you as the caregiver and for the person with dementia by being prepared. To prepare for the move ahead of time, follow these tips:

Changes that a move brings can be upsetting so many families may avoid talking about it. However, once you start a discussion, it gets easier. Family members who are less involved in caregiving or live out of town may not fully appreciate the need for a move. Consider asking them to help with some of the direct caregiving tasks, share information about the disease, and encourage them to take part in the moving process.



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Valuable items can get lost in the long-term care home so avoid bringing them (e.g., jewelry, medals, watches, etc.).

Try to save a few vacation days in case the move comes up suddenly. Remember to have money saved to pay for the home's first month rent and any other services that the person with dementia may need (e.g., phone, cable television). Also, pre-arrange for a family member or friend to be available on standby to care for children or give a hand, if necessary.

On the moving day, staff need to know what your wishes are if the resident's condition worsens. Make sure to discuss the following care options with family members so that on moving day you can answer all of the home's questions about future care:

Ask the home about specific processes and procedures related to the move and see if you can do any of them ahead of time like doing paperwork before moving day. Also check whether you can prepare the room ahead of time by moving anything in or decorating.

- Key contacts
- Power of attorney
- List of medications and previous health assessments (if available)
- Medical coverage and insurance benefits
- Medical treatments
- Advance care directives or living will

Take the time to sort through treasured items during this waiting time. Talk with the person with dementia and other family members when deciding what items to bring to the long-term care home, what items to store, and what items to give away. Familiar belongings may help the person feel more at ease and adjust to the new environment. Consider bringing the person's own bedding, photographs, radio, music or a favourite pillow. Some find comfort by holding body pillows or a familiar stuffed toy. These items can also help personalize the room. Sometimes it is helpful to give the staff a recording of your voice to play for the person.

Source: Adapted from Community Care Access

Centre (CCAC) webpage at www.healthcareathome.ca

See the next page for tips on how to address common concerns about preparing for a move. To learn more try the interactive and informative e-learning module created by Alzheimer Society of Ottawa and Renfrew County called *Transition to Long Term Care*.

Essential items may include medications, clothing (labeled), toiletries and personal items such as incontinence products, emergency phone numbers, medical coverage cards, MedicAlert® Safety Home® bracelet, equipment or aids (e.g., hearing aids), and batteries. Check out the *Packing for Moving Day* list created by Alzheimer Society of Ottawa and Renfrew County.



Tips for preparing for a move

Common concerns about preparing for the move	Tips to help address your concerns
I don't know what to expect.	<ul style="list-style-type: none">• Visit or call the home and ask what you can expect on move-in day:<ul style="list-style-type: none">- Can a staff member or volunteer give me and the person with dementia a tour of the home?- Which staff will be available on moving day to help the person with dementia while I am taking care of paperwork?- What should I pack for moving day and is there anything I shouldn't bring?- Do I need to bring a list of the medications that the person with dementia is taking?- Do I need to bring incontinence products for the person with dementia?- Do I need to label all of the person's belongings?- If some clothing doesn't need a label, what happens when it is laundered?- Whom should I ask for when we arrive?- Should I bring a void cheque for automatic payments?
I'm working/ travelling/ have child care responsibilities and am not sure how I can be available on short notice.	<ul style="list-style-type: none">• Try to save a few vacation days for the time of the move.• Tell the homes (that have your name on the waiting list) how to contact you if you are travelling.• Arrange for a family member or friend to be available on standby to care for your child during moving day.• Contact local moving companies to learn about their process.
I don't know what my role will be after the person moves into the home.	<ul style="list-style-type: none">• Discuss with a social worker at the home about what they expect of family members regarding providing support for the person with dementia.• Do this e-learning module called Transitioning to Long Term Care to learn about possible changes in your role and relationships which can be found at Alzheimerottawa.ca/transition

<p>I'm not sure how to feel like a member of the care team.</p>	<ul style="list-style-type: none"> • Build relationships with the staff and regularly communicate with the team. • Consider getting involved in the daily life of the home by joining the home's Family Council or volunteering to give tours for potential residents and their families. • Share your knowledge of the person with dementia and your experience of caring for them with the home's care team at the initial care planning meeting.
<p>I'm not sure what to do if I have questions or concerns about the care provided in the long-term care home after the move.</p>	<ul style="list-style-type: none"> • Think about your expectations and what is reasonable and work with staff to improve the person with dementia's experience. • Speak with the Social Worker or Director of Care about specific concerns. • Acknowledge that staff members are trying hard to provide the best possible care; treat them with respect and appreciate their efforts. For example, saying "thank you" goes a long way!

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Handling moving day


This information is for you if you are caring for someone with Alzheimer's disease or other dementias and you are moving them to a long-term care home. From talking to families, we know that 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 provides you with tips to make the moving day as successful as possible.



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To make the moving day as successful as possible, follow these tips:



with the person by saying, for example, "We are going to a place you can stay, a place where they will call me if you need me" or "I've found a place where you will be well taken care of, where I can visit you often and make sure you have everything you need". Emphasize the positive aspects such as socializing and enjoyable activities.

The person's reaction to moving may range from anxiety and agitation to withdrawal. When you and the person with dementia arrive at the home, take some time to show them around the room and common areas of the home. To comfort the person, say and do what you feel is best. Remember to ask a staff member to accompany the person while you do the necessary paperwork.

Ask a family member or

The person with

friend to go with you for support or plan to have someone at home when you return so you are not alone.

dementia may get upset when you leave so it can be helpful to think of a distraction to ease the process. Ask about recreational activities that the person can participate in.

Ask if

People with dementia need support throughout the transition to a long-term care home from

you can reserve the room by paying for it before the actual moving day. Allow plenty of time for paperwork and ideally, to help decrease stress, see if you can do it before the moving day.

everyone in their support network like family and friends. To learn more about supporting the person on moving day, try the interactive and informative [e-learning module](#) created by Alzheimer Society of Ottawa and Renfrew County called Transition to Long Term Care at www.alzheimerottawa.ca/transition

Recognize that

you are dealing with a stressful situation and that all emotions are normal. There is no right way to feel about the move. Some caregivers feel anger, grief, and embarrassment, loss of control or relief. Speak with someone you feel comfortable with to help you process your range of emotions.

peace of mind, after the move when you get home, consider checking with your staff contact to see how things are going.



What to Bring on Moving Day – Checklist

Item	Action	✓
Furniture	Ask the home if you can bring personal furniture	
All about me	Fill out and print a copy of <i>All about me</i> to share with the staff	
Clothing	Label clothing and make a list Check out the Packing for Moving Day list created by Alzheimer Society of Ottawa and Renfrew County	
Accessories	Bring outdoor clothing, hat, gloves, boots, umbrella, etc.	
Personal grooming	Bring all personal grooming and toiletries items (tooth brush, comb, make-up, etc.)	
Assistive devices	Bring assistive devices and batteries <ul style="list-style-type: none">• hearing aids• glasses• dentures• walker• Other	
Legal and financial documents	Bring copies of all of the completed legal and financial documents <ul style="list-style-type: none">• Power of attorney• Medical coverage• Insurance benefits	
Calendar of upcoming events	Make a calendar of upcoming events and medical appointments and update it regularly	
Medical file	List current medications and bring them in original containers Bring the most recent health assessments	
Advance care plan	Bring a copy of your family member's advance care plan (including wishes for medical interventions) Advance care directives or living will	
MedicAlert Safely Home bracelet	Ensure the MASH subscription and file are up to date	
Key contacts	Print a list of key contacts in case of an emergency	
Valuables	Do not bring any valuables (jewelry, etc.); these should be kept with family or in a safe.	
Other	Ask the home if you can bring special equipment, such as radio, TV, telephone, cell phone, etc.	

Moving day can be extremely tiring and bring a sense of loss. Contact a friend or family member if you feel you need support. The Alzheimer Society is here to help you transition through this difficult time.

Alzheimer *Society*



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Adjusting after a move

This information is for you if you are caring for someone with Alzheimer's disease or other dementias after a move to a long-term care home. From talking to families, we know that moving the person you care for to a long-term care home and adjusting to the many changes may be one of the most difficult stages you experience. This information covers things to think about and hands-on tips to help you and the person with dementia adjust after a move.

It will take time for both, you and the person with dementia, to adjust to the new living situation. Although you should expect a period of adjustment, the person with dementia will eventually settle. To help things go smoothly during the first few weeks after the move, follow these tips:

- Keep reassuring the person with dementia by telling them how much you care.
- Familiarize yourself with the home and make an effort to get to know the staff, management, residents, and other caregivers.
- Consider joining the person with dementia for a few meals in the dining room with other residents. This can help the person get used to the new surroundings and meet other residents.
- Try to attend care plan meetings, family council meetings, and possibly join in social activities.
- Another way to get involved is to help with tasks such as mealtimes and personal grooming. Before taking on any particular role, discuss it with the care team.



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Give yourself some time and remember that you have not lost your role as a caregiver, you now share the responsibility of care with others. To provide ongoing support for the person with dementia, follow these tips:

- Share your knowledge about the person with the staff such as life-long habits, likes, dislikes, daily routines and ways to avoid episodes of agitation. You may find the Alzheimer Society's *All about me* [Alzheimer.ca/allaboutme] booklet useful for recording this information and sharing it with staff.
- Discuss options for meeting the person's needs and preferences. Ask questions if you need complicated words or procedures explained.
- Tell staff your feelings and concerns like what help you need or questions you may have. Maintain realistic expectations of the staff and the home.
- Keep up to date with the doctor and staff about the person's condition, care, and treatment. Ask for a copy of the care plan.
- Ask to have regular care planning meetings attended by both family members and care providers. Remember, you are partners in the person's care team.
- Treat the staff—health care aides, nursing staff, activity staff, housekeepers and volunteers—as individuals and build relationships with them.

Even people who are well into the later stages of dementia still have feelings; everyone needs to feel supported. Visiting is an important way for you to support the person with dementia and stay connected now that you are no longer providing day-to-day care. Visiting may be emotionally difficult for some people. It is important to do what feels right for you.

Visits can be:

- A way to continue life-long routines: Schedule visits around activities like sharing a meal together.
- A social time: Consider timing your visit to participate in a group activity such as a musical event.
- A chance for some more personal time: enjoy quiet times alone together reading or reminiscing.
- A way to build connections: consider having other family members visit, such as children to help the person feel more connected.
- An outing to an art gallery or to a local garden. Remember to discuss your plans with the staff before the outing.

There may be many people visiting at different times. To help you and the person with dementia remember who visited and the details of the visit, create a *visitor guest book*. Check with the staff first to see if it is possible to leave a visitor guest book in the person's room.

If visiting is not an easy option due to distance, try recording your voice or sending pictures of you and other family members so the person continues to feel connected.

During this transition, it will take time to adjust to your new schedule. Providing care for someone with dementia takes a tremendous toll on your physical and emotional health as the caregiver. However, it is common to be so involved in caregiving that you may overlook caring for yourself.

To actively care for yourself, try these self-care tips:

- Maintain and rebuild the connections that are important to you. For example, think about your interests and hobbies and consider contacting some friends or joining clubs, etc.
- Seek out support because it is one of the most important ways to come to terms with the feelings of loss and grief that are often part of caring for someone with dementia. It is important to reach out to individuals in your life who are your “psychological family,” meaning the people you naturally turn to in times of crisis and celebration. Identify the people in your life who are there for you in good times and bad. These are people who may be in the strongest position to understand you, acknowledge your remarkable efforts and successes, and give vital support.
- Keep in mind that whatever you are feeling, it’s normal; you may feel lonely or empty without the person or you may not have these feelings. Also, remember that not all caring relationships are loving and close. If your relationship with the person with dementia is difficult, it is natural to be sad about not having a more positive relationship with them.

• Try to be realistic about the nature of dementia. Sometimes caregivers expect that the person will improve under the care of professionals. However, the dementia will continue to progress regardless of where the person lives. Continue to learn about the disease and how to support the person through each stage.

Give yourself some time and remember you have not lost your role as a caregiver; you are now sharing the responsibility with others. You and the person with dementia will be facing different experiences and will need time to adjust to the changes after the move. To help address your concerns about settling in, consider the following tips.



Common concerns about settling in	Tips to help address your concerns
I'm not sure how long it will take the person with dementia to adjust to their new environment.	Try to be patient as the person with dementia settles in. For some, it may take weeks or months and for others, less. Communicate closely with the staff during this adjustment period. On the other hand, the person with dementia may adjust quite well to their new surroundings. This may leave you with mixed emotions. These feelings are completely natural. Remember, you have not lost your role as a caregiver, you are now sharing the responsibility with others.
I don't know how to react if the person asks difficult questions or says things like "I want to go home."	Find out what may be triggering difficult questions or statements. Is the person feeling unsafe? Sometimes the person simply needs reassurance.
I'm not sure how often I should visit.	Visit as often as you want and stay for as long as you feel comfortable. For some people, caregiving has been so demanding that they need a break during the first few weeks after moving. Others want to visit as often as possible during the first few weeks. The important thing is to make each visit –regardless of length or frequency – as full and rewarding as possible for both of you.
I'm not sure what to do if the staff provides care differently than what the person is used to.	Acknowledge that there will be differences between the caregiving routine at the long-term care home and how you cared for the person in your home. Share your knowledge about the person with staff.
Now that I'm not responsible for day-to-day care, I'm not sure what my role is.	Focus your time and energy on providing the person with a sense of belonging and love that no one else can give. If you wish to continue to contribute to the physical care of the person, negotiate what your role with the staff. Allowing others to take responsibility for the day-to-day caring tasks does not make you a less important caregiver.

Ideas for spending time together:

- Look at photos.
- Go for a walk.
- Listen to music.
- Hold hands.
- Brush the person's hair or massage their hands with a perfumed cream.
- Rummage through interesting items that have meaning for the person (e.g., a variety of fabrics for a sewer or baseball memorabilia for a sports fan)
- Enjoy painting or creating something.
- Share a snack.
- Read aloud from the newspaper or from a favourite book.
- Visit a garden.
- Do tasks like folding towels.
- Walk around the home and meet other residents.
- Watch a DVD series.
- Read aloud letters or emails from friends or listen to a taped message or voicemail.
- Pre-arrange to call a friend or family member.
- Sit where you can see activities like at a window overlooking a busy street or a garden with a birdfeeder.

"Keeping my mother happy was all that mattered. If something made her happy, like a strawberry ice cream treat or listening to music, we always tried to do that. – a caregiver in Nova Scotia, Canada

Need more information?

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