

Handout for Individuals & Caregivers: Long-Term Care

When a person living with dementia needs more support than is possible, moving to a long-term care home may be next step for you and your family. Long-term care homes are places where adults can live and receive help with most or all daily activities and access to 24-hour nursing and personal care.

Moving to a long-term care home is not an inevitable step, but it needs to be considered and discussed within the persons future care plan. It may be necessary to consider more than one move throughout their future planning, perhaps from family home to supportive housing to retirement home and finally to long term care.

As a caregiver you should not consider a move as a failure or selfishness. Recognize that it is a common step for many in the overall progression of the disease. In fact, 57% of seniors living in a long-term care home have a diagnosis of dementia.

Moving someone you have been caring for can bring about many emotions including guilt, sadness, relief, or even second thoughts. It is important to understand that these are all normal reactions. It does not mean that your role as a caregiver is any less important. In fact, you may find that this move allows you to shift your focus from providing care to staying connected and engaged with the person.

Reach out to your friends, family, doctor, or even a caregiver support group if you need any help with making the decision to move.

REASONS FOR CONSIDERING A MOVE

- You may consider a move for a variety of reasons:
- The condition of the person living with dementia has worsened or difficult to manage behaviours have emerged.
- They may have been in hospital with a further decline in their health or function 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 or another 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.

If you require additional support, and you are concerned that staying at home is no longer possible, we recommend you explore all your options.

Handout for Individuals & Caregivers: Long-Term Care

WHAT IS A LONG-TERM CARE HOME?

Long-term care homes are residential homes that provide ongoing care to patients whose care needs cannot be met in the community. People may require this level of support due to advancing age, disability or declining health.

Long-term care homes are places where adults can live and receive:

- Help with most or all daily activities
- Access to 24-hour nursing and personal care

You can expect much more nursing and personal care here than you would typically receive in a retirement home or supportive housing.

People whose health-care needs can be managed at home or who need help with specific day-to-day tasks, like bathing, dressing or cooking, may be able to receive support at home through home care services.

If an older adult needs only occasional health-care support and can live in a relatively independent fashion, a retirement home may be a more appropriate option.

ELIGIBILITY

To live in a long-term care home, you must:

- Be age 18 or older
- Have a valid Ontario Health Insurance Program (OHIP) card
- Have care needs including:
 - 24-hours nursing care and personal care
 - frequent assistance with activities of daily living
 - on-site supervision or monitoring to ensure your safety or well-being
- Have care needs which cannot be safely met in the community through publicly funded community-based services and other caregiving support
- Have care needs which can be met in a long-term care home

COSTS

All personal and nursing care provided by long-term care homes in Ontario are funded by the government. The individual must pay for accommodation charges such as room and board. These costs are often higher for semi-private or private accommodation.

Handout for Individuals & Caregivers: Long-Term Care

SERVICES AND FACILITIES

Long-term care homes usually offer the following:

- Shared dining room, TV rooms and other living areas
- Nursing and personal care on a 24-hour basis
- Access to health professionals
- Individual care plan (reviewed every 3 months)
- Basic furnishings (e.g., bed and chair)
- Meals (including special diets)
- Bed linens and laundry
- Personal hygiene supplies
- Medical/clinical supplies (e.g., walkers and wheelchairs for occasional use)
- Housekeeping
- Individualized religious and spiritual services
- Social and recreational programs
- Medical services
- Assistance with activities of daily living

Optional services are usually available for a fee such as hairdressing, cable TV, telephone services and transportation.

HOW TO APPLY?

All applications and admission to long-term care homes are arranged by Home and Community Care Support Services organizations. To start this process:

Call your local Home and Community Care Support Services organization

Your local Home and Community Care Support Services will help you every step of the way. Home and Community Care Support Services staff will:

- Determine your eligibility
- Tell you about homes in your area

Handout for Individuals & Caregivers: Long-Term Care

- Tell you about costs
- Help you apply

To contact your local [Home and Community Care Support Services](#): Enter your postal code online then call 310-2222 (no area code required)

Choose the right long-term care home

To find a home that offers the care you are looking for, you should:

- Consider what your priorities, expectations and what can be afforded.
- 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 do not forget to ask anything important. Ask about the services, policies, and costs so you are ready to decide quickly when a room becomes available. Some long-term care homes allow the person living 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 living with dementia
- Read the [Ministry of Long-Term Care's report](#) about each home

Apply for care

Once your local Home and Community Care Support Services organization has determined that you are eligible, you can apply to a maximum of **5** homes. Your local Home and Community Care Support Services organization will coordinate your application for you.

Waiting for an offer

If your application is accepted by the home(s), you may have to wait until a bed becomes available. The waiting time depends on:

- The number of beds available in the home
- The type of bed you have requested
- Whether the bed you have requested is in a private, semi-private or basic room

Handout for Individuals & Caregivers: Long-Term Care

Home and Community Care Support Services staff will contact you when a bed becomes available. You have 24 hours to accept or reject the offer.

- If you accept the offer, you have up to five days to move in.
- If you refuse the offer, your application to all chosen homes will be cancelled. In this case, you cannot re-apply for 12 weeks after the day you were removed from the waiting list, unless there is a significant change in your condition or circumstances.

[For more questions, contact your local Home and Community Care Support Services organization.](#)

PREPARING FOR A MOVE

You can make the move easier for you as the caregiver and for the person living with dementia by being prepared. This will help you to make a quick decision when an offer is made. To prepare for the move ahead of time, follow these tips:

- **Talk to family:** Be open with family members; talk about the decision and the upcoming move. Family members who are less involved in caregiving or live out of town may not fully appreciate the need for a move.
- **Visit the homes:** Depending on the stage of the disease and if appropriate, arrange for the person living with dementia to visit the homes that you are considering for them. It is important to make the person feel as comfortable as possible with the move that may come up suddenly.
- **Talk to your employer:** If you work, consider talking with your employer about the possibility that you may need some time off with very little notice. Try to save a few vacation days in case the move comes up suddenly.
- **Save money:** You will need money to pay for the first month's rent and any other services that the person living with dementia may need (e.g., phone, cable television).
- **Arrange childcare:** Pre-arrange for a family member or friend to be available on standby to care for children or give a hand, if necessary.
- **Talk to the home:** After you have accepted an offer, ask the home what you can do before moving day. 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.

Handout for Individuals & Caregivers: Long-Term Care

- **Identify important items to be moved:** Take the time to sort through treasured items. Talk with the person living 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.
- **Gather essential items:** 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.
- **Put away valuable items:** Items can easily be misplaced in a long-term care home.
- **Make care decisions before the moving day.** 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:
 - Key contacts
 - Power of attorney and Advance Care Plan
 - List of medications and previous health assessments (if available)
 - Medical coverage and insurance benefits
 - Medical treatments

MOVING DAY

To make moving day as successful as possible, consider these tips:

- **Explain the move simply and gently** to the person living with dementia. Emphasize the positive aspects such as socializing and enjoyable activities. The person's reaction to moving may range from anxiety and agitation to withdrawal.
- **Walk around the home:** When you and the person living with dementia arrive at the home, take some time to show them around the room and common areas of the home. Remember to ask a staff member to accompany the person while you do the necessary paperwork.

Handout for Individuals & Caregivers: Long-Term Care

- **Try to schedule the move over a few days to give you time to prepare.** Ask if you can reserve the room by paying for it before the actual moving day. Ask if you can complete the paperwork prior to moving day.
- **Discuss with staff how you will leave the home after the move.** The person living with 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.
- **Get the staff contact information.** For peace of mind, after the move when you get home, consider checking with the staff contact to see how things are going.
- **Be ready for an emotional day:** 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, embarrassment, loss of control or relief. Speak with someone you feel comfortable with to help you process your range of emotions.
- **Take care of yourself.** Ask a family member or friend to go with you for support or plan to have someone at home when you return so you are not alone.

ADJUSTING AFTER A MOVE TO LTC

- Keep reassuring the person living with dementia by telling them how much you care.
- Familiarize yourself with the home and try to get to know the staff, management, residents, and other caregivers.
- Consider joining the person living 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.
- Help with tasks such as mealtimes and personal grooming. Before taking on any particular role, discuss it with the care team.

CONTINUING SUPPORT

- 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 living with dementia, follow these tips:

Handout for Individuals & Caregivers: Long-Term Care

- Share your knowledge about the person with the staff. You may find the Alzheimer Society's All about me booklet useful for recording and sharing information about the person's life-long habits, likes, dislikes, daily routines and ways to avoid episodes of agitation.
- Discuss options for meeting the person's needs and preferences. Ask questions if you need complicated words or procedures explained.
- Talk to staff about any concerns and try to 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.

MEANINGFUL VISITS

Visits can be:

- A way to continue life-long routines. Schedule visits around activities like sharing a meal together.
- A social time. Participate together in a group activity such as a musical event.
- A chance for some more personal time. Enjoy quiet time alone together reading, looking at photos, or reminiscing.
- A way to build connections. Invite 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.
- To help you and the person living 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.

Handout for Individuals & Caregivers: Long-Term Care

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 sewer or baseball memorabilia for a sports fan)
- Walk around the home and meet other residents.
- 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.
- 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.

YOUR OWN ADJUSTMENT

- Maintain and rebuild the connections that are important to you (e.g., think about your interests and hobbies and consider contacting some friends or joining clubs, etc.).
- Seek out support. 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.
- Remember 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 living 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.

Handout for Individuals & Caregivers: Long-Term Care

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 living with dementia will be facing different experiences and will need time to adjust to the changes after the move.

ADDITIONAL RESOURCES

- A By Us For Us Guide: Living Safely the-ria.ca/wp-content/uploads/2018/11/BUFU_LivingSafely_eversion_A.pdf
- Dementia and Living Alone archive.alzheimer.ca/sites/default/files/files/national/brochuresconversations/conversations-about-dementia-and-living-alone.pdf
- The Stages of Alzheimer's Disease alzheimer.ca/en/about-dementia/what-alzheimers-disease/stages-alzheimers-disease
- Local Alzheimer Society www.alzheimer.ca/helpnearyou or call 1-800-616-8816
- The MedicAlert® Safely Home® program www.medicalert.ca/safelyhome
- Dementia and Personal Care www.alzheimer.ca/personalcare
- Driving and Dementia alzheimer.ca/sites/default/files/documents/conversations_driving.pdf
- A Guide to Programs and Services for Seniors in Ontario www.ontario.ca/document/guide-programs-and-services-seniors

REFERENCES

1. Brender, F., Gutoskie, H., Hopewell, R., & Hounam, B. (2014). A By Us For Us Guide: Living safely. Retrieved from the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-Safely_AODA.pdf
2. Alzheimer Society of Canada. (2018). Dementia and living alone. Retrieved from archive.alzheimer.ca/sites/default/files/files/national/brochuresconversations/conversations-about-dementia-and-living-alone.pdf