

CAREGIVING OPTIONS: CONSIDERING LONG-TERM CARE

As Alzheimer’s disease or other dementias progress, a person’s abilities change. Eventually, full-time care will be needed. The person will require help with everyday activities, including bathing, dressing, eating and using the bathroom. Providing this support on a day-to-day basis can be exhausting. When considering how best to meet the needs of the person with dementia, it is important to think about what’s best for the person while also evaluating the impact that caregiving is having on your own well-being.

Experiencing some stress is part of everyday life. However, when symptoms of stress persist, they can be harmful. The following checklist may help you identify how stress is affecting your life. Place a checkmark to indicate how often you experience these symptoms of stress.

Caregiver Stress Checklist (Excerpt from <i>The Alzheimer Journey: At the Crossroads</i>)	Never	Sometimes	Often
Loss of sleep <ul style="list-style-type: none"> • Are you experiencing difficulty getting to sleep? • Do you wake up in the middle of the night? • Do you have stressful dreams? 			
Personal health <ul style="list-style-type: none"> • Have you gained/lost weight recently without intending to? • Do you get ill more often than you used to? • Have you developed chronic health problems (e.g., backache, headaches, high blood pressure)? 			
Emotional health <ul style="list-style-type: none"> • Do minor incidents make you cry, angry or unusually irritated? • Are you having difficulty controlling your temper? • Do you feel pressure to hold things together? • Are you feeling hopeless about your current situation? 			
Loss of interests <ul style="list-style-type: none"> • Have you given up hobbies or interests that you once enjoyed? • Are you spending less time with others? 			

If you answered “sometimes” or “often” to many of the questions above, you may need to seek help to care for yourself. Even with the help of support services, providing care to a person with dementia can be overwhelming. No matter how close you may be to the person, you may want to consider including others in the caregiving role.

Caregiving options

Programs for people living with dementia will be available in your community. Adult day programs and volunteer visitors can provide stimulation and the opportunity for the person to participate in meaningful activities. Depending upon where you live, short-term (respite) and permanent housing options may include supportive living, group homes, retirement residences or long-term care homes. Your local Alzheimer Society will have information on the services that are available in your area. In making your decision, try to remain flexible and keep in mind the needs of the person you’re caring for.

When looking at caregiving options, it is important to remember that there are no right or wrong choices. Each caregiver will make a decision based on their own particular situation. For some, the decision will be to continue providing care at home or in the community. For others, the choice will be made to arrange for care provided in a long-term care home.

Learning more about the disease and being able to talk about your feelings can often help to clarify your decision. Alzheimer’s disease will eventually require full-time caregiving and you can’t do it alone. Your friends, family and members of your support group can be especially important during this time.

If you decide to continue caregiving at home, it will be important to know about the support services that are available. In-home respite services, a home-care worker or visiting nurse can provide you with relief from caregiving tasks. At the same time, you might wish to consider enlisting additional support for day-to-day chores such as housekeeping, laundry and home maintenance. The Alzheimer Society can inform you of the available services in your area.

If you decide to arrange for care in a long-term care home, there are a number of things you can do to make this decision easier -- both for you and for the person with the disease.

Making the decision

Making the decision to move the person you have been caring for to a care home is one of the most difficult decisions you will have to make. However, it may also be one that is necessary, both for your well-being and that of the person you are caring for.

Being prepared can help make this decision less stressful. Often, when a vacancy becomes available in a long-term care home, you will be required to make the decision about accepting it quickly. It is important, therefore, to familiarize yourself with the long-term care homes in your area and ask questions about the services, policies and costs of the care home beforehand. This will help you to make the best decision.

A number of people can help you in your search for an appropriate long-term care home. These may include your local Alzheimer Society, support groups, friends or family, doctors, faith leaders, social workers, social service agencies, or local organizations for seniors.

Assessing a long-term care home

Contact your local Alzheimer Society for information about the long-term care application process in your area. Some communities will have a number of homes to choose from. Once you have

compiled a list of long-term care homes in your area, call and ask some general questions such as: Is there a waiting list? What is the cost for living at the care home, including the cost of extra care as the disease progresses? Will the person with Alzheimer’s disease or other dementias be able to live there throughout the course of the disease? You should be able to narrow your list based on the answers you receive. When you have shortened the list, you will want to visit the care homes yourself. If appropriate, you may wish to consider having the person you care for come with you during the visit. You will have your own set of priorities to consider, and some of your expectations may be more important than others. Keep these in mind as you begin your search.

The following are general questions that may be helpful in assessing the quality of each of the care homes you visit. Don’t forget to pay attention to your “gut” feelings as you begin to tour; they can be very helpful in determining if a care home is appropriate for the needs of the person you are caring for. You may find it useful to bring along a friend or family member for input and support as you visit each home. Talking to the residents and their family members can also be helpful.

Area of concern	Questions to ask
Location	Is the care home conveniently located? Will you be able to visit easily? Does public transportation run nearby?
Appearance	Are the kitchen, day rooms and bedrooms clean and tidy, and free from unpleasant odours?
Menus	Is the menu varied, nutritious and tasty? Can the care home accommodate special dietary needs? Is food available throughout the day? Is snacking possible? Are mealtimes flexible?
Bathrooms	Are they private? Are they clean? Are they easy to find? Are there grab bars and other safety devices present?
Dementia-friendly	Are staff specially trained to care for someone with Alzheimer’s disease and other dementias? Is there ongoing staff training about the disease? Is it “home-like”? Is there a separate unit for residents with dementia? Can the residents walk safely indoors and outdoors?
Resident-to-staff ratio	What is the resident-to-staff ratio? What proportion of residents have Alzheimer’s disease or other dementias?
Interaction	Do all staff interact with residents on a regular basis in a friendly and personable manner?
Activities	Are there a variety of meaningful activities for groups and individuals? Are there therapeutic activities, such as music, pets, horticulture? Are there opportunities to socialize? Is there flexibility in the routine?
Visiting	When can you visit? Can you have privacy with the resident? Can you take the resident for outings?
Understanding behaviour	Do staff try to understand what residents are communicating through their actions? (such as a person pacing because they are looking for a family member). Restraints should not be used without first exploring all alternative ways of responding to a person’s behaviour. (Restraints may include physical restraints, like a geri-chair; chemical restraints, like sedatives; or restraints to the environment, like a locked door.)
Safety	Are there smoke detectors and sprinklers? Are there slip-proof mats in the baths, grab rails, etc.?

Quality	Is the care home accredited by an independent body? What were the results of the most recent provincial inspections?
Medical care and continuum of care	Can you continue to use your own doctor or is there a resident doctor? Is there a doctor on call? How often does the doctor visit? Can you meet the doctor? How are medical emergencies handled? Are there situations where the care home will no longer be able to provide care to the person?
Care philosophy	Does the care home focus on individual resident needs? Can it accommodate flexibility in routines? ("My mother has never been a morning person.") Are there regular care planning meetings that include family members?
Individualized care	Is consideration given to individual cultural, religious or spiritual needs? Are other languages spoken?

Even after an extensive search, be aware that you may not find everything you want in a single care home. Try to remain flexible. Ask yourself how you feel about working together with staff to meet the needs of the person with dementia. Moving to a long-term care home does not mean that your role as a caregiver is any less important than before. You may find that you have a different focus such as staying connected to the person and advocating for quality dementia care.

You can promote quality care for the person with the disease by sharing the Alzheimer Society's *Guidelines for Care* framework and the PC P.E.A.R.L.S™ with staff. A copy is available from your local Alzheimer Society. Your local Society can also provide staff training and education.

If you make the decision to arrange for care in a long-term care home, see the information sheet *Adjusting to Long-term Care* for advice on preparing for the move and helping staff get to know the person with Alzheimer's disease.

Need more information?

Contact your local Alzheimer Society for information and support. Visit our website at www.alzheimer.ca.

Resources:

- ¹ *Guidelines for Care: Person-centred care of people with dementia living in care homes.* Alzheimer Society of Canada, 2011.
- ² *PC P.E.A.R.L.S™: 7 key elements of person-centred care.* Alzheimer Society of Canada, 2014.
- ³ Alzheimer Society of Ottawa and Renfrew County, *Transition to Long Term Care* <http://alzheimerottawa.ca/get-help/education/learn-online/interactive-learning/transition-to-long-term-care/>

Alzheimer Society

Alzheimer Society of Canada
 20 Eglinton Avenue West, 16th Floor, Toronto, Ontario, M4R 1K8
 Tel: 416-488-8772 1-800-616-8816 Fax: 416-322-6656
 E-mail: info@alzheimer.ca Website: www.alzheimer.ca

Facebook: www.facebook.com/AlzheimerSociety Twitter: www.twitter.com/AlzSociety

