Transitioning a Person With Dementia From Independent Living To Long Term Care

John O'Keefe, MSW, RSW

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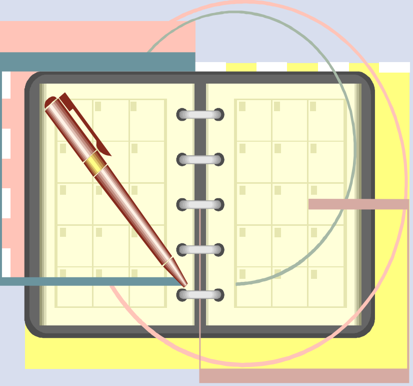
Alzheimer Society



Agenda

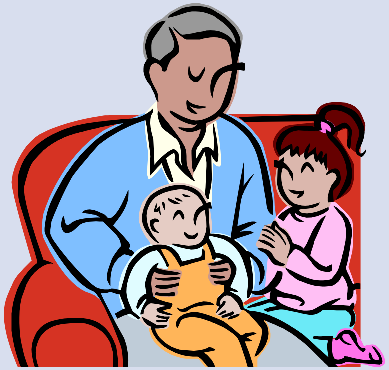
- Introduction
- Conversations Surrounding Care
- Pre-Admission Planning
- Admission
- Visitation
-Post Admission
- Family/Friend Involvement
- Rising Tide Report

Introduction

The goal of those of us serving in the continuing care sector is always to maintain the independence of persons living with dementia for as long as they can be safe and well in the community

There are many ways that this can be accomplished as the cognitive decline of a loved one progresses:

- Personal emergency response systems, sensors and smart home technology
- In-Home Supports with professional care providers
- Assisted Living, Supportive Housing, Enriched apartment programs
- Co-habitation with a relative or friend, if possible



Changing Symptoms/ Changing Needs

- Communication/Language Difficulties
- Anxiety/Restlessness/Sleep Disturbances
- Marked decrease in Memory
- Marked change in Personality
- Paranoid and Delusional Symptoms
- Increased Physical Care
- Incontinence
- Marked Disorientation & the Need for Full Time Supervision

Caregiving Considerations

- Is safety or space an issue?
- Is the care becoming more complex?
- How is your health: physical & emotional?
- Are specialized services, products needed?
- Are you able to balance the responsibilities to include other family members?
- Are you able to meet the demands of your job?
- What resources are available to help?

When do we need to get help? Summary

- Is the health of the person with dementia or your health at risk?
- Are their any safety concerns?
- Does the person with dementia need more care than he/she is receiving right now?
- Is your care giving role becoming more difficult?
- Can you name an issue where you are having difficulty and can use additional help?

Tipping the Balance from Independent Living to Long Term care

- These are the behaviors that I typically observe than result in a family/friend caregiver no longer be capable of continuing with a caregiving arrangement:
- Night time waking/wondering
- Gross incontinence
- Immobility/inability to weight-bear/transfer
- Unsafe behavior (esp. related to cooking)

There comes a point in the care of a loved one with dementia that the benefits of continuing to live in the community are outweighed by the advantages of living within care.

We would not hesitate to contact 911 in the event of an acute care emergency because most of us recognize that we do not have the ability to care for a loved one who is experiencing an acute event. However, many persons are reluctant to access LTC when they are not capable of managing the chronic care needs of a loved one.

Why are so many of us willing to access acute care so easily and yet many of us are reluctant to access LTC?

- Caregivers are reluctant to relinquish care because of a perception that they should be able to look after someone with chronic care needs
- Permanent nature of LTC versus perceived temporary nature of acute care hospitalization
- Stereotypes of LTC as being "warehouses for the elderly"
- LTC services providers must do a better job of providing person-centered care

Placing a loved one with dementia in LTC will impact the entire family. There will be a transition period not only for the person entering, but for family and friends as well.

The transition of a loved one to LTC is a major life event in the life history of a family

It may create a fracture in family/friend relationships or it may bring loved ones closer together

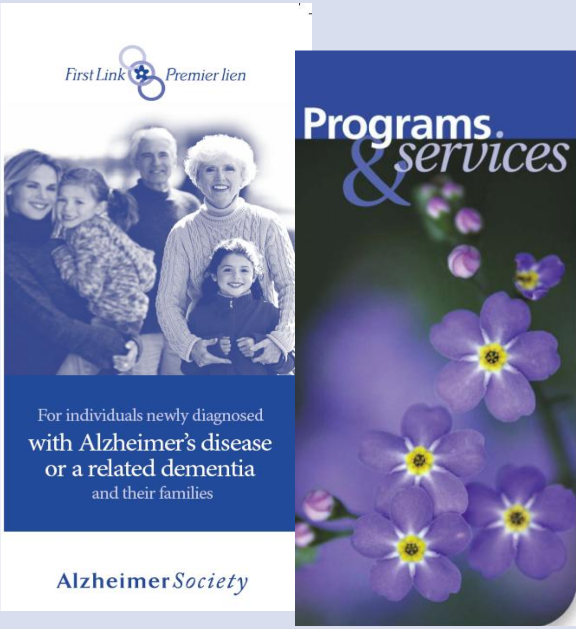
Often times Long Term Care (LTC) placement is made in the midst of a health crisis, leaving little time for a choice between options. However, when you do have time on your side there are many steps you can take to make the transition to long term care go smoother.

Conversations Surrounding Care

Planning for a LTC admission, when possible, makes the transition to placement a much smoother process.

It is most beneficial, but often extremely difficult, to discuss options for care with relatives while they are cognitively aware.

ASC has many useful materials which can help stimulate these conversations. Our Day to Day publications entitled “Caregiving Options: Considering Long Term Care” and “ Adjusting to Long – Term Care are valuable resources to support these conversations

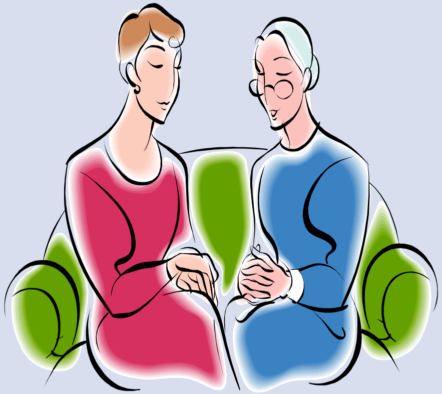

First Link Premier lien

For individuals newly diagnosed with Alzheimer’s disease or a related dementia and their families

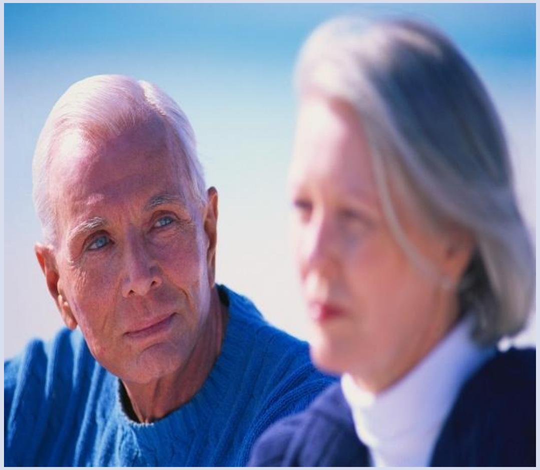
Alzheimer Society

Programs & services

This conversation, while frequently difficult, may actually be comforting for the cognitively aware individual requiring placement who now knows that their family will attempt to meet their wishes. The relative arranging placement will be reassured that they are aware of their loved ones wishes should the need for placement arise.



Much of the stress that family members and friends describe with placement comes from not being aware of their loved ones preferences when they are confronted with having to make placement choices.



Many times, discussions surrounding the need for LTC for persons with dementia can evoke negative responses. This is to be expected when a manifestation of the dementia illness is lack of insight and judgment into ones needs for care.

Frequently, as well, persons with memory issues forget the conversation shortly after it has occurred.

These are situations in which discussions about a move to long term care only serve to agitate the person requiring care. In these circumstances, you may choose not to have detailed dialogue about a move before it takes place.

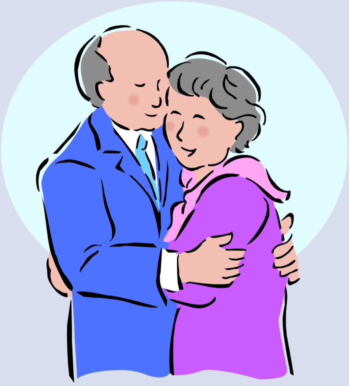
Pre-Admission Planning

- When the opportunity exists, do your research. Investigate nursing home options. Visit facilities **unannounced .** Drop in as if you were visiting a resident. Travel the corridors observing the interactions between staff and persons who live there. Speak to the persons that live there and ask them if they are contented. Talk with other family members who have persons living there to find out what they think.

- Visiting at mealtime, when staff tend to be working very hard, is recommended. Assess whether staff are able to manage the workload and the morale at these “peek” time
- Are volunteers considered a part of the staff complement and valued for their contribution to the community
- The more “institutional” a place feels, the less “**person-centered”** it is

Guidelines For Care

- The ASC Guidelines for Care : Person Centered Care of People with Dementia living in Care Homes initiative can be used to reinforce the cultural change which is underway in LTC communities across the country



If your loved one is cognitively aware and, if the opportunity exists, take them to see the community as well. You may arrange to have lunch in the community if facilities exist for use by the general public.

- If possible, their first visit to the home should not be of the day they are moving in
- If your loved one is unable to visit prospective homes take photographs and/or access information from websites

If possible, try to place a loved one in a nursing home in relative close proximity to family members and friends to maximize the possibility of visitors.

- When possible attempt to complete the paperwork associated with an admission ahead of time
- Attempt to understand the financial implications of the placement. Be clear on what is covered and what is not covered in the accommodation charge

Clarify if your loved ones family doctor will be able to care for them.

Admission

Most persons with dementia adjust to living in an environment with other individuals who are at similar stages in their cognition.

Persons with dementia who have had prior experiences with respite admissions and/or participation in adult day support programs may experience a smoother transition to LTC placement.

- Every admission is unique but, in general, the persons who transition most effectively are those who have family/friends accompany them on the day of admission.

When possible the room should be arranged prior to admission. If not done in advance, family members and friends are encouraged to spend time helping to arrange the room at the time of admission, meeting with other persons who live there, as well as caregivers

The room should be filled with personal items that make your loved one feel more at home

Photos, a comforter, favorite chair and clothing items are desirable

Items must be identified with you loved ones name

Providing as much personal information as you can to the caregivers enables caregivers to better relate to your loved one, thereby easing the transition. Provide information on the following area to the caregiving staff:

Medical issues
Nutritional status
Mobility status and specialized equipment needs
Personal Care/Activities of Daily Living
Living Environment
Cognitive Status
Spiritual Needs
Lifestyle Choices
Hobbies and favorite pastimes

It may be necessary to shorten your visit on the day of admission if your loved one is very agitated or upset. If your loved one is angry of abusive try not to take their comments personally. My experience is that persons who live in LTC tend to become most angry at those who they know will always be there regardless of the treatment they receive.

Remain positive. Often times, a LTC community provides more stimulation than a person living alone receives. Social engagement, cognitive stimulation, and physical activity are all demonstrated to assist with maintaining brain capacity. These activities are all available in LTC for those who choose to participate.

When it is time to leave staff can assist you with your departure if necessary. Check back with caregivers by phone to make sure your loved one is settling in after you leave.

Discuss with staff your loved ones reaction after your departure. I often observe family and friends who are most distressed because their loved one is upset by their leaving. They may actually forget that they were upset shortly after the family or friend left.

VISITATION

Visit at various times of the day and on various days of the week. Frequent visits will reduce feelings of abandonment that persons living in LTC sometimes experience and ease the transition to placement. Those who are unable to visit should be encouraged to call, e-mail, send letters, and photographs to residents who can still appreciate this type of contact.

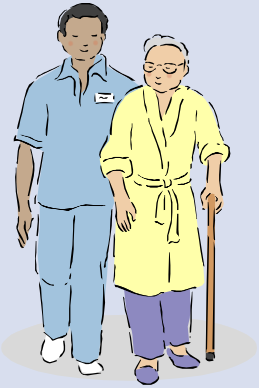
It is often a good practice to call prior to a visit. It helps prepare you when you know, in advance, the type of day your loved one is experiencing.

Plan visits around activities that are taking place within the community. Keep track of events listed on bulletin boards and newsletter throughout the community.

I’m frequently asked if a relative can overdo visiting. Only you know the amount of visiting which is appropriate for you and your loved one. If you have been a primary caregiver, it is difficult to adjust to a new routine where you no longer have the primary responsibility for the physical care of your loved one. You need to remain intimately involved the life of your loved one while at the same time practicing self care.

Post Admission

Your loved one will require time to adjust to their new surroundings. This is particularly true for those with cognitive impairment. Routines are changed, caregivers are different, and there are new neighbors to get to know.



If your loved one is experiencing a difficult adjustment to LTC, avoid the temptation of thinking that you might have made a mistake . Each person’s transition is individual. It take times to settle in and there is no “magic remedy” to assist with the adjustment.

"Don't expect miracles"

Sometimes a manifestation of a dementing illness is a change in personality. However, most often the personality remains essentially unchanged. Therefore if your relative is a private person there is a good chance they will behave similarly in LTC. Conversely, if the are outgoing, they often become very involved in the life of their new community. I frequently encounter family and friends who have expectations that their loved one will become someone they are not when they come to LTC

Family/Friend Involvement

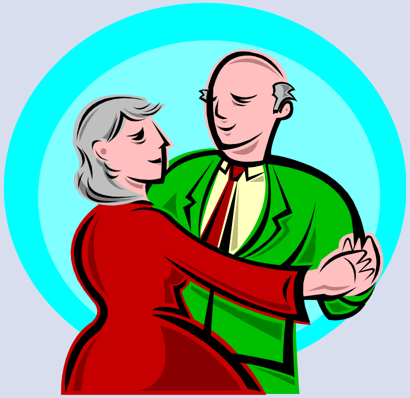
Your caregiving responsibly does not terminate upon the admission of a loved one to a LTC community. The caregiver continues to live with the feelings and emotions of their loved one following admission.

Continue to depend on your available family and friends for support post admission.

If you are experiencing emotions related to the placement that you are finding difficult to cope with arrange to meet with the Social Worker if one is available. If not seek out a counselor or confident elsewhere. Remember that it is perfectly normal to experience these feelings as well.

Being the caregiver to a loved one in the community is an overwhelming physical and emotional responsibility. Relinquishing the primary responsibility for care to the professional care providers in LTC is not easy after providing constant care. It requires a period of adjust for you and your relative.

Stay involved in the care to the extend that you are comfortable and is permitted. Use the time and energy you gain from being freed up from the physical requirements of care to re-focus on the emotional aspects of the relationship.



Remain in regular communication with the caregivers. Sharing your insights into your strategies for care of your loved one. Take the opportunity to compliment staff who provide care in a compassionate manner

Do not hesitate to point out areas for improvement to staff and administration. Most reputable care providers are aware of their accountability to you and welcome this feedback.

Become involved in the community in which you loved one is living. One option is to join the family council should one exist. Family Councils exist as an advisory body to management. Council members have the opportunity to provide input into the care and quality of life of the persons who live there. They organize events for family and loved ones.

Attend information nights or family orientation meetings if they are offered. Familiarize yourself with the family handbook if one exists.

- Attend any interdisciplinary care conferences that are convened to discuss the care and quality of life of your loved one. These are tangible examples of how the care of your loved on is delivered in partnership with you.

You will need to familiarize yourself with an entire new system involved in the care of your relative. You should expect that your loved one will be at the center of a circle of care and their friends and family will be partners in this relationship. Within this model the person living in community is in control of their decisions and their wishes are observed to the extend they can maintain autonomy. They are treated with dignity and respect

RESPECT

Transitions do not end at the time of admission to the LTC community. The nature of dementia is that it is a progressive illness. Behaviors change as the illness advances; some escalate others wane, recognition of loved ones may diminish as the disease progresses, new relationships form, end-of-life considerations can come into play.

You need to be prepared to deal with these changes as part of the ongoing transition which accompanies dementia.

Rising Tide Study: Getting started

As the voice for people living with dementia, the Alzheimer Society saw the need for better understanding of the impact of the disease on Canadians

In 2008, the Alzheimer Society secured public and private funds and commissioned ***Rising Tide: The Impact of Dementia on Canadian Society***

Report released January 4, 2010

What *Rising Tide* says: Incidence

- **Incidence: Number of new cases of dementia per year**
- The number of new cases of dementia in 2038, among Canadians (65+), is expected to be 2.5 times that for 2008

- ***Projected incidence:***
- 2008: 103,700 new dementia cases per year or ***one new case every 5 minutes***

- 2038: 257,800 new dementia cases per year or ***one new case every 2 minutes***

What *Rising Tide* says: Prevalence

- **Prevalence: Number of People with Dementia**

- By 2038, the number of Canadians (of all ages) with dementia is expected to increase

  to 2.3 times the 2008 level

– **Projected Prevalence:**

2008: 480,600 people, or ***1.5% of the Canadian population***

2038: 1,125,200 people, or ***2.8% of the Canadian population***

What *Rising Tide* says: Caregiving

Dementia prevalence is classified into three care types:

1. People receiving care in long-term care facilities (i.e. nursing homes)
2. People living at home and receiving community care
3. People living at home and receiving no formal care

Shift toward home/community-based care

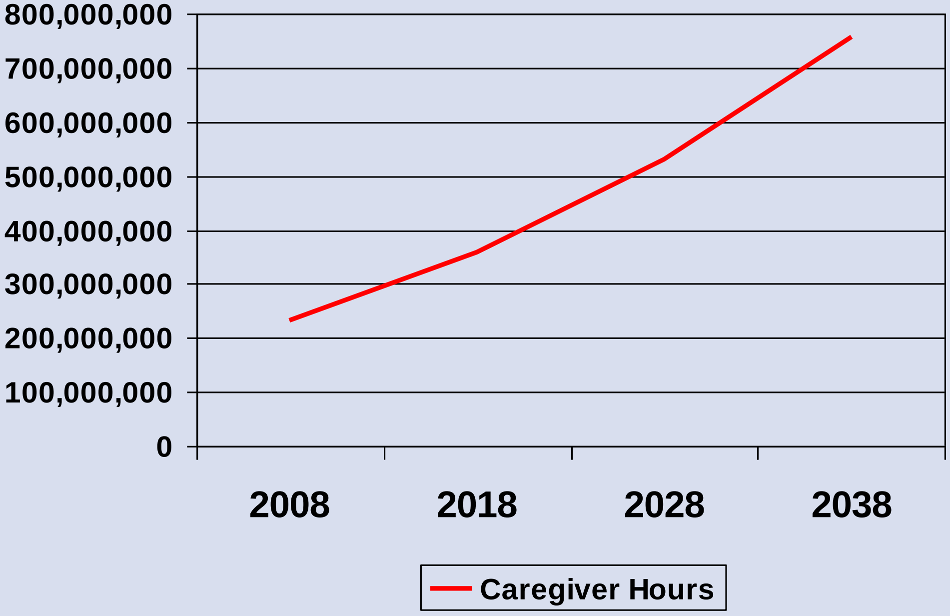
- Number of long-term care beds expected to grow from 280K in 2008 to 690K in 2038
- Based on projected demand, this creates a shortfall of 157K beds in 2038
- Increase in Canadians (65+) living at home with dementia is therefore expected to jump from 55% to 62%

Given the increasing prevalence of the illness between now and 2038; we will not be able to construct a sufficient number of LTC beds to care for persons with dementia. We need to pursue other models for the delivery of LTC apart from the traditional model of institutional care

- As care shifts away from care facilities there will be an increase in the need for family-based care.

- The number of hours spent on family-based care is expected to more than triple by 2038.

What *Rising Tide* says: caregiving



Sources

- *Family Caregiver Education Series.* (2009). Alzheimer Society of Nova Scotia
- Rising Tide: The Impact of Dementia on Canadian Society. (2008). A Study Commissioned by the Alzheimer Society of Canada

Wrap Up

Questions/Comments

Thank You For Your Attention and Participation

JOHN O’KEEFE, MSW, RSW
jokeefe@nwood.ns.ca
Phone: 454-3355
Fax: 453-1178