

FROM



TO RETIREMENT HOME

*A Guide for Caregivers of Persons with
Dementia*



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We acknowledge the contribution of family caregivers who prefer to remain anonymous.

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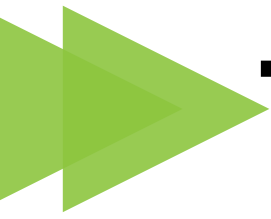


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What Is This Guide All About ?

This guide is for caregivers of persons with dementia who are considering a move to a retirement home (or a retirement residence). The term “caregiver” is used here to include family members, friends, and any other unpaid individuals who support a person with dementia. Although written for caregivers, the guide is a useful resource for professional service providers who assist persons with dementia and their caregivers. Portions may also be useful to persons in early stages of dementia who wish to be active participants in the process.

This guide begins with the information on **“Why a Move May Become Necessary”** and it ends with suggestions on **“How to Support the Person after the Move”**. It is intended to give you basic information that you need as you go through the process and to direct you to the people and services that can further help you get more specific advice, guidance and support. You may choose to read the entire guide or focus on the section(s) that may be of particular interest to you.

Throughout the guide, we have included information to help you better understand and relate to the unique challenges that persons with dementia may experience, and suggest ways to support them during this transition.

In writing this guide, we have tried to use simple, respectful and sensitive language. To this end, we have consulted many guidelines, including:

- the Alzheimer Society of Canada’s language guidelines
- the Government of Canada’s recommendations on how to communicate in print with/about seniors.

For an easy read, throughout the guide, “he” is used to refer to a third person in a generic manner and without a sex differentiation.

This guide draws information from many sources, such as:

- other documents written for older persons (and their caregivers) moving to a care facility
- research findings, including our own studies on the needs and experiences of older persons (and their caregivers) moving to or living in a retirement residence
- clinical expertise of many professional service providers who help older persons and their caregivers in this journey

The comments of persons with dementia and their caregivers used throughout this guide come from the participants of a study and do not belong to the individuals in the photos.

We would like to thank all individuals who generously shared their personal experiences, knowledge, and insights with us. We are particularly grateful to those who took the time and interest to review the guide and to give their valuable suggestions.

Finally, we have included a short form at the end of this document to ask for your feedback and any suggestions you may have to improve future revisions of this guide. We sincerely hope that you find this guide helpful.

Thank you,

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Comments of a person with dementia:

“I know that I got into some jams there for a while. I was dragging my feet and life didn’t look all that exciting. I can’t cook, I can’t clean. I do nothing at home. You worry: ‘my gosh, I really should be doing so and so’. I wonder if I ordered my gas and paid my phone bills. So, that’s when we decided ‘let’s go have a look at some homes’. It makes life easier, because your mind takes little ‘day trips’....”

Comments of a family caregiver:

“She sees me more frequently, several times a week: taking her to the doctor, buying stuff for her, just popping in. It’s difficult for her, but it’s also becoming difficult for us, her living here independently. Because I respond to all the calls. It’s doable, but it’s more and more difficult because as more time goes on, the simpler things, like food and stuff, are becoming a bigger issue. So for that, we said ‘look, even if you stay here today, how long do you think you can continue?’. I think we’d have to face this decision anyway. The better time to face it is now when she is not in a critical condition.”

Why A Move May Become Necessary

The majority of older persons wish to remain in their own homes for as long as possible. Early in the course of their illness, it is often possible for persons with dementia to live in their own homes (as long as they receive adequate supervision and support). As the disease progresses, staying at home may no longer be a practical, safe or desirable option for the person or the caregiver(s).

Dementia is a disease that affects the chemicals and structure of the brain. Alzheimer's disease and stroke-related dementia are the most common of a large group of brain disorders known as "dementia". Many problems commonly experienced in dementia can seriously limit the person's ability to safely and independently perform everyday tasks at home. Examples of such problems are:

- increasing forgetfulness
- misplacing things
- difficulty performing familiar tasks (e.g., cooking, cleaning, driving, shopping, taking medications, etc.)
- loss of initiative
- disorientation to time and place
- difficulty concentrating
- deficits in thinking and judgment

Dementia is a condition that will worsen over time. The symptoms and speed of change are different for each person. It is impossible to tell how fast any one person will progress through the stages. The stages of a dementia disease are commonly named as "early", "middle" and "late". People in early stages of the disease have mild impairments and are often able to live at home with some supervision and help from family/friends and community support services (see "**How to Make the Right Decision**" Page 7). As the disease progresses to the middle stage, memory and functional abilities worsen and the person needs closer supervision and assistance with many daily tasks. At this stage, if the person lives alone, staying at home may be possible only with substantial outside support. In the late stage, people with dementia become unable to look after themselves and need care 24 hours a day. To learn more about dementia disorders and their progression, contact the Alzheimer Society (see "**Quick Reference**, Page 38).

The “right” time to move from home to a more supportive living environment (such as a retirement residence) is different for each person with dementia. There are many things that should be taken into consideration when making such an important decision. The chart below presents some of the signs that suggest the person with dementia is having difficulty living safely and independently at home.

Health and Safety

- Being unable to prepare and eat nutritious food:
 - forgetting meals
 - having an empty fridge
 - keeping rotten food in the fridge
 - experiencing unexplained weight loss
- Forgetting to take medications as prescribed by doctor or making mistakes in taking medications
- Having falls and other accidents at home
- Creating unsafe situations, such as leaving on a kettle, oven or stove
- Having difficulty handling emergencies:
 - not knowing what to do in case of a fire
 - being unaware of 911 emergency number
 - having difficulty using a telephone
- Getting lost on familiar streets
- Making frequent visits to hospital emergency room
- Caregiver(s) being concerned about leaving the person alone

Home Maintenance

- Having difficulty managing everyday household tasks:
 - unkempt living environment
 - piling up of dishes and laundry
 - rotten food in fridge
 - unopened mail
 - unpaid bills

Self Care

- Gradually losing the ability to look after oneself, such as **being unable to:**
 - regularly take a bath/shower
 - groom and dress properly
 - maintain standards of hygiene

Social Connection

- Being unable to leave home and maintain social interests:
 - gradual withdrawal from social activities
 - complaining of loneliness
 - becoming more isolated
 - being afraid of being alone

The ability of a person with dementia to remain at home also largely depends on the support available from family/friends and community services. As a caregiver, you need to openly and honestly ask yourself some important questions when deciding whether it is time for the person to consider an alternative living arrangement:

- What is the effect of caring for the person at home on my life?
- Do I have the physical and emotional resources to meet the person's present and growing future care needs at home?
- Do I feel stressed and overwhelmed with my caregiving responsibilities?
- What are other available sources of support (e.g., family, friends and community support services)? Have we taken full advantage of them?
- Does the person accept receiving outside help at home?
- Is the outside help enough to meet the person's present and future needs?
- What is the financial cost of arranging for adequate home care and supervision?
- Overall, does living at home compromise the physical and emotional health of the person with dementia or mine as a caregiver?

Some people may choose to move to a retirement residence before moving is absolutely necessary. There may be many reasons to make such a decision. For example, some may wish to free their time and energy from burdensome household chores and take advantage of social activities offered in these places. Others may choose to move to a residence earlier in the course of the dementia illness, while they still can actively participate in the decisions and more easily adjust to the change. We will further discuss some of these issues in the next sections.

How To Make The Right Decision

Helping an older person with dementia to make a decision to move out of his own home may be one of the most difficult responsibilities for the caregivers. To make the right choices, it is important to plan carefully and timely. As difficult as it may be, a discussion of the care and housing needs of a person with dementia should begin as soon as possible (see also **“Why a Move May Become Necessary”, Page 4**).

Delaying this discussion and the necessary planning until a crisis happens will:

- leave you unprepared
- limit the time you have to explore the best options
- limit the choices available to you
- make the transition more difficult for you and the person with dementia

It is best to make plans while the person can still take part in the decisions, such as:

- choice of an alternative living arrangement
- selection of a residence
- distribution of personal belongings

The person can then more easily adjust to the change in his place of residence.



Comments of a family caregiver:

“It happened so quickly, I just sort of made a snap decision: ‘OK, that’s it, we can’t do this at home anymore’. If I thought things out a little longer I might have made some better choices. You don’t do enough research, I find, until you are in a crunch position and you have to do it quickly. You’re not aware of what’s out there as far as support and what’s available....”

The decision should begin with a careful evaluation of the person's housing and care needs and preferences. Early in the process, it is very helpful to consult trusted and qualified health professionals to ask for their advice on the person's needs and the available services. In particular, it is important to speak to the person's family physician in order to thoroughly evaluate his condition and to find out if there are any reversible causes for his decline. In complex situations, the family physician may decide to arrange for a comprehensive assessment by a team of health professionals who are specialized in the care of older persons. Caregivers themselves can also directly contact these specialized geriatric services to see if the person qualifies for a referral (see **"Quick Reference", Page 38**).

You may also want to speak with other professionals who are informed about the services available to older persons with dementia: e.g., the staff of the Alzheimer Society, community care coordinators, home care case managers, public health or community health nurses or social workers, hospital discharge planners, etc. (see **"Quick Reference", Page 38**).



As a caregiver helping a person with dementia make the right choices, you need to educate yourself about the range of housing and care options available in your region. Your choice will depend on many factors, including the care needs and preferences, support systems, and financial resources of the person. Here is a short summary of some of the main options available to you.

1. Community Support Services

Various public, non-profit, private, and volunteer agencies in the community have services to help frail older persons remain in their homes safely and comfortably for as long as possible. Examples of such services are:

- meal preparation and delivery services
- homemaking and home maintenance
- personal care, nursing and rehabilitation services
- transportation
- shopping
- security checks
- friendly visits
- emergency response systems
- wandering person registry
- adult day centre programs
- respite care services

(for more details on these services see “Quick Reference”, Page 38)

These services can be very helpful in the early to middle stages of dementia, but may become insufficient or too costly as the disease progresses (particularly, if the person lives alone).

Depending on the person’s (and your own) needs, you may want to consider the use of some of these services while you are exploring your options, making a decision, and/or preparing for a move to a care facility.

For more information about these services and the eligibility for publicly funded programs in Ontario, contact your local Community Care Access Centre (CCAC) (see “Quick Reference”, Page 38). In Ottawa, call the Champlain CCAC **613-745-5525**. In other communities in Ontario, visit website www.ccac-ont.ca or call **416-310-CCAC** to find the closest CCAC to you. In other regions of Canada, contact government agencies that provide home care in your area.

If you live in Ottawa, you may also want to get a comprehensive list of services available in the Directory of Resources for Senior Citizens of Ottawa, published by the Senior Citizens Council on Aging (visit website www.seniorcouncil.org or call **613-234-8044**). Similar directories may be available in other regions of Canada.

Finally, your local Alzheimer Society can inform you about support services available to the persons with dementia and their caregivers. In Ottawa, contact the Alzheimer Society of Ottawa and Renfrew County (visit website www.alzheimer-ottawa-rc.org or call **613-523-4004**).

In other regions, contact the Alzheimer Society of Canada for information on the local agency in your community (visit website www.alzheimer.ca or call **1-800-616-8816**).

If the person needs (or prefers) to move to a care facility, there are at least three types of supportive living options available:

- retirement residences or retirement homes (sometimes also called residential care facilities or assisted living facilities),
- long term care (LTC) homes (in the past they were referred to as nursing homes or homes for the aged), and
- affordable supportive housing

The main differences between these options are the levels of care available and funding sources (see the charts below for more details).

2. Retirement Residences or Retirement Homes

These are mostly private residences that typically offer a set of six main services in a more or less home-like environment: accommodation, meals, laundry, housekeeping, activity programs, and some level of personal/health care services (e.g., help with bathing and other personal care tasks, access to professional nursing, medication supervision and administration, on-site medical clinics, etc.).

In many regions of Canada, including Ontario, retirement residences are not regulated or funded by the government. So, there are major differences in their sizes, prices, policies, amenities, programs and services.

Some residences may not have the staff and services necessary to meet the needs of persons with dementia when these needs increase. Others may have “assisted living” programs or “dementia care” units that can better accommodate the needs of persons with dementia and other disabilities. These higher levels of care, if available, are usually offered for an extra fee.

Generally, most retirement residences prefer to admit older persons who are relatively independent for personal care (e.g., toileting, feeding, dressing, bathing, and walking). In fact, most require a medical report of the person’s health and care needs before accepting an application. Some may not accept persons who have a diagnosis of dementia.

Residents of retirement homes may still be eligible for government funded home care programs. In Ontario, contact your local CCAC for more information (see **Quick Reference, Pg 38**).

An application has to be made directly to each residence. Some places may have a waiting list. Although, these are usually much shorter than those for LTC homes.

In some regions, there may be non-profit retirement homes or municipal government subsidized accommodations in selected residences available for low income seniors. Contact your local social service office for more information. In Ottawa, call the City of Ottawa, Supported Living Services at **613-560-0622 (x 26586)**.

Retirement residences are not currently regulated by the provincial government. They are accountable to the Ministry of Housing under Residents' Rights Act, 1994. In Ontario, they have to follow a set of legislations, such as the Residential Tenancies Act and Health Promotion and Protection Act.

Many retirement residences are voluntary members of the Ontario Retirement Communities Association (ORCA). This is a non-profit and self-regulatory organization which sets standards of care, inspects, and accredits member retirement homes (visit website www.orca-homes.com or call **1-800-361-7254**).

3. Affordable Supportive Housing

These are mostly independent apartments with a care component, such as meal preparation (and/or communal dining), homemaking, social/recreational programs, and 24-hour emergency response. Typically, the levels and types of services available are not sufficient to adequately meet the complex needs of persons in middle and late stages of dementia (particularly if they live alone).

The funding may come from various sources, such as Ministry of Health and Long Term Care, municipal governments, and various non-profit organizations.

There are differences in ownership, care services available, costs, and policies of these homes (including the application process and eligibility requirements for subsidies).

For more information, contact your local government agencies that are in charge of social housing programs and/or home care services in your region. In Ottawa, you can call the Champlain CCAC and/or the City of Ottawa, Supported Living Services (see above).

4. Long Term Care Homes (LTC)

These are generally facilities for frail persons who need help with personal care and 24-hour professional nursing supervision. Many have specialized units for the care of persons with advanced dementia.

LTC homes are funded and regulated by the provincial governments. Typically, the resident pays for the accommodation and the government covers the cost of care. Subsidies are available for those who are unable to pay.

In Ontario, CCAC determines the eligibility for an admission to a LTC home. Because of the shortage of long term care beds, there may be a long waiting time (of over one year) for admission to a LTC home. Given the progressive nature of dementia, even if the person does not currently need to move to a LTC home, you may want to consult with a CCAC case manager to ask about the application process to a LTC home in the years to follow (see **“Quick Reference”, Page 38**). You may also find the following document useful in making your decision: *“When Home is no Longer an Option: A Journey of Acknowledging, Adapting, Adjusting, and Accepting”* (visit the Alzheimer Society of Ottawa and Renfrew County website www.alzheimer-ottawa-rc.org or call **613-523-4004**).

A person’s unique needs, preferences and resources will determine whether or not a retirement residence is the right choice for him. For many persons in early to middle stages of dementia, it can be the right choice. For those with more advanced dementia it may no longer be a practical, affordable, and/or safe option. As the disease progresses, it reaches a point when the complex needs of a person with dementia can no longer be adequately met in a retirement residence, and living in a LTC home may be a better choice.

In the meanwhile, some persons with dementia (with the help of their caregivers) may choose to move to a retirement residence. Depending on the circumstances, this may be a safer and more comfortable alternative to the person living at home (see **“Why a Move May Become Necessary”, Page 4**). This choice also creates an opportunity for the person to participate in the social activities that are often offered in these places. It can also benefit the caregivers by reducing their responsibilities. This can free their time and energy to spend more quality time with the person during their visits.

When choosing a retirement residence for a person with dementia, look for places that can offer higher levels of care, should the person’s needs grow as the disease progresses. This choice is important in order to save the person and yourself the trouble of having to go through multiple housing transitions in a short period. Educate yourself about the policies of your chosen retirement residence with regard to the cost and process of accessing extra services, such as “dementia care” and “assisted living” services (see **“How to Choose the Right Place”, Page 21**).

Although each situation is unique, it is very important to make sure that a person with dementia is given the opportunity to participate in the decision making process, as much as possible (depending on the person's ability to understand the situation and the consequences of the decisions made). Involve other caregivers and close family members in the decisions and planning process, as appropriate. Discussing the issues openly can help lessen the anxieties and fears that you, the person with dementia, and other involved individuals may have. Holding a joint meeting to openly discuss the needs and concerns of all parties can be very helpful. Once again, you may want to involve an objective third party, such as a trusted qualified professional, in the meeting.

An experienced professional can:

- inform you about available options
- offer sound advice
- support and validate your decision
- help the person with dementia and all the caregivers come to an agreement
- better prepare the person and the caregivers for the transition



Comments of a family caregiver:

“Since my mother’s death, I’ve had virtually daily contact with my father, because he seems to be confused about so many things these days. My brother and I were struggling: ‘Okay, so how do we convince this man that he shouldn’t be living at home’. That’s when we talked with the family doctor and she suggested she could arrange this geriatric assessment. We didn’t even know that it had existed until we talked to the doctor. All we knew was that something had to be done and we would much prefer that it come from an official source than from us”

What Emotions To Expect And How To Cope

The decision to move to a retirement residence may be an emotional one for the persons with dementia and their caregivers. Some individuals may be ready for and even welcome a change in their living arrangement. Others may be very reluctant to make such a decision. It is important to find out the underlying reasons for the reluctance. Below is a list of potential reasons to consider.

The inability of a person with dementia to fully understand the vulnerabilities, risks and dependencies that he is experiencing due to the effect of the illness

A genuine belief of the person that the decline is part of normal aging which simply has to be accepted and tolerated

An expectation of the older person that the family should support him to remain at home, just as he might have taken care of his relatives in the past

A strong emotional bonding with one's home and the people, activities, belongings and experiences associated with living at home

The lack of information (or even misconceptions) about alternative housing options

An emotional reaction of denial often caused by the overwhelming fear of negative consequences of moving to a care facility:

- loss of familiar routines and valued lifestyles
- loss of control, autonomy and privacy
- fear of being institutionalized and abandoned by family

Feeling overwhelmed with the available choices, decisions to be made, and planning/preparations required

Concerns about the cost of living in a care facility, becoming financially dependent, and/or being unable to leave an inheritance for their children



Listen carefully to the person's needs, concerns and expectations. Tell the person that you understand this is a difficult decision to make. Do not discourage the person from expressing any feelings and concerns. This information can be very useful to you as you try to help the person make the right choices and adjust to the change. With time, patience, education, and support most concerns can be addressed. If the decision to move to a retirement residence is not urgent, be patient and persistent: the person with dementia may need extra time to think through all the information and be able to develop a rationale for the decision.

Help the person weigh the risks and benefits of each alternative option. If he tends to focus mostly on the losses associated with a residential change, highlight the potential gains with a sense of enthusiasm. For example, you can point out:

- comfort of living in a more supportive and protected environment
- opportunity for more social stimulation
- possibility of becoming less dependent on family/friends for everyday tasks

Do not argue with the person, but present the facts honestly. You may need to repeat your thoughts, because he may forget the past conversations. Discussing issues openly, honestly and jointly can make your relationship even stronger. It may also ease some of the person's anxieties about losing control and autonomy in the process.

Comments of a person with dementia:

“I was going through emotions. My heart wasn’t in it. There are many things to do, you know, you gotta sell the house, you gotta move, but you’re just going through the emotions. It’s the end of an era. It’s only bricks that stay there. But it’s your home, your husband, your family. You cherish that first house, memories of your family....”

In most cases, with early planning and enough support, persons with dementia are able to accept the new realities, make the right choices, and get used to the change. Some individuals may benefit from participating in support groups, and/or may need professional support and counseling during this period. For more information on services available in your region, contact your local CCAC or the Alzheimer Society (see **“Quick Reference”, Page 38**). The Alzheimer Society offers information, counseling and educational sessions for persons with dementia and their caregivers to help them better understand the disease and to improve their problem solving and coping abilities (see **“Quick Reference”, Page 38**). Many persons with dementia and their caregivers find these sessions very helpful in understanding what is happening to the person and how to best support him.

Comments of a family caregiver:

“It’s been a little bit difficult, because I didn’t know how to deal with it sometimes. I’ve got frustrated with her reasoning or her decision. But, as more time goes on, I’m realizing that a lot of it has to do with her kind of naivety about the situation. She doesn’t really understand a lot about what’s going on. So, it’s becoming easier for me to deal with it. It’s like: ‘Okay, I understand. I can’t get mad at her if she’s confused, because it’s just part of the phase she’s at’. I’m hoping it’ll all play out fine and I’m sure it will, because she’s very adaptable....”

If the person continues to have difficulty making the right choices, and his decision making capacity is in question, the primary caregiver has the responsibility to take action on behalf of the person. This is particularly important if the person is at risk of causing harm to self or to others (see **“Why a Move May Become Necessary”, Page 4**). In this situation, if you already have a Power of Attorney, this is the right time to activate it. A “capacity assessor” can help you evaluate the person’s capacity in making housing and care choices. If you are a family caregiver and do not have a Power of Attorney, you can still act as a substitute decision maker on behalf of an incapable relative. A CCAC case manager can tell you more about your rights and responsibilities in either situation. For more specific information on legal matters, you can also contact the Office of Public Guardian and Trustee (in Ontario, visit website <http://www.attorneygeneral.jus.gov.on.ca> or call **1-800-891-0506**). This office can also give you a list of qualified capacity assessors in your area (for more information see **“Quick Reference”, Page 38**).



Comments of a family caregiver:

“With the assessments, they advised me that living at home was really no longer an option for her. There were real concerns about her safety. At this point, of course, she was saying, ‘No, I’m not going anywhere’. I feel sad and guilty sometimes: ‘should I really be doing all this?’ I mean, it’s been explained to me, if I’ve got the Power of Attorney for her personal care I have to make sure that she’s well cared for. I think, probably, I would have spoken to her a lot more about it earlier on, before she started to really get forgetful. I think I would’ve done more of that, trying to encourage her to make the decision herself”

Do not delay the process of planning and decision making. With early planning, a person with dementia will have a better chance to:

- more actively participate in the process
- be able to make more informed choices
- have the time to more gradually prepare for the transition

Having to make an urgent decision on behalf (or even possibly against the wish) of a person with dementia can be a very stressful and traumatic experience for the caregiver(s). In this situation, it is even more important to reach out for help. The person's family physician, a CCAC case manager, the staff of Alzheimer Society, and specialized geriatric services are examples of the professional providers that can help with these difficult situations (see **"How to Make the Right Decision" Page 7**).

This can be a long, intense and very emotional process for you as a caregiver. During this period, you may experience a range of emotions, such as:

- sadness and grief
- guilt and feeling that you have somehow failed the person
- frustration and anger toward the person and/or other involved caregiver(s) (particularly if there are conflicts of opinions)
- feeling overwhelmed and burdened with the responsibilities.

These are normal reactions. If you are a spouse caregiver, the decision can have even greater consequences for you, regardless of whether or not you are planning to move with your partner or choose to remain in your current residence.

Acknowledge your feelings and talk to trusted people in your network of friends and family. Consider joining a support group for caregivers and/or talk to a counselor who has experience of helping persons with dementia and their caregivers during these types of transitions. Once again, do not hesitate to contact your local Alzheimer Society for more information about educational, counseling and support services available to you (see **"Quick Reference", Page 38**).

To avoid a burnout and to have the resources necessary to help the person with dementia, you should first meet your own needs. Persons with dementia can notice the signs of stress in their caregivers and can react negatively. Finding ways to reduce your stress can benefit all involved. Think of the next few years as a marathon: pace yourself, so you can make it to the end! Take care of yourself and do not hesitate to ask for help from family/friends and community support services.

How To Plan To Look For A New Place

You and the person with dementia have now made a decision to help him move to a retirement residence. The next step is to start looking for the right place and to prepare for the move. This can be a busy, and depending on the circumstances, stressful period for both of you. Plan ahead, ask for help, and have realistic expectations of yourself and the person with dementia. Many caregivers tend to underestimate the time that is needed to complete all the tasks, and hesitate to ask for outside help. Similarly, they tend to overestimate the ability of the person with dementia to share the responsibilities. This may result in a delay in the process, and unnecessary stress for all involved.

Prepare a list of everything that needs to be done during this period. As much as possible, try to share the responsibilities with close family/friends who are willing to help, as well as with the community support services. If you are employed, you may want to let your employer know about your new responsibilities, and find out about the possibility of taking some time off during this period.

While you are looking for the right residence, it is very important to make sure that the person's current home is as safe and supportive as possible. If you have not already contacted the CCAC to learn about available community support services, you should consider doing so now (see the chart on "**Community Support Services**", **Page 9**).

The CCAC case manager may also arrange for a home safety assessment to find and remove any safety hazards that may place the person at risk for fire, falls and other accidents. If you wish to learn more about home safety for persons with dementia, there are many user friendly guides available. An example is the document named "*At home with Alzheimer Disease: Useful adaptations to the home environment*", published by the Canada Mortgage and Housing Corporation (visit website www.cmhc.ca or call **1-800-668-2642**). For more information on this topic, contact your local Alzheimer Society (see "**Quick Reference**", **Page 38**).

Consider encouraging the person to have a trial or a “short-stay” in a retirement residence during this period. This can have many benefits:

- it will give you a break from your day to day caregiving responsibilities
- it will give the person an opportunity to have first hand experience of living in a retirement residence before the decision for a permanent move is finalized
- it can help the person get used to the new environment more gradually, easing the transition from home to a retirement residence



Comments of a family caregiver: “She had tried this particular retirement home for a month, just to see how she felt about it. So, she was aware of where the place was, what it was like and she knew a lot of the staff. I wanted that familiarity for her. But, we went and looked at other ones too. With a friend, we just split apart the list. So, we got down to some busy work. I wanted to give her some options, what she wants, what she doesn’t want, if there is something better out there. We did it and I think it was a benefit to her. It educated both of us as to what’s out there....”

How To Choose The Right Place

When helping a person with dementia find a retirement residence, you are looking for a place that can best re-create a personal sense of “home” for him. So, it is very important to try to include the person in the process as much as possible. Encourage the person to express his needs, preferences and expectations. Consider your own needs and goals, as well as those of other caregivers and close family members who may be affected by your choices. Give special attention to the needs of a spouse who may be moving with the person with dementia to a retirement residence.

Balance the needs and expectations of everyone involved and make a realistic list of the key qualities of a retirement residence that you should be looking for. No one facility can meet all your needs, but select one that best meets your top priorities.

Get an updated list of all retirement residences in your region. In Ottawa, most of them are listed in:

- “Directory of Resources for Senior Citizens of Ottawa”
(visit website www.seniorcouncil.org or call **613-234-8044**)
- “Directory of Housing and Residences for Senior in Ottawa”
(visit website www.coaottawa.ca or call **613-789-3577**)

Your local CCAC can also give you a list of retirement residences in your area. Finally, ORCA publishes a directory of member retirement residences in Ontario (see **“Quick Reference”, Page 38**).

The reputation of the residence, the recommendations of service providers, and a quick internet search of the residences’ websites can help you make a short list of selected places to look at more closely. The following chart presents some of the main qualities of a residence that you may want to consider in making your selection.



Location

One of the most important features of a residence that you need to consider in making your selection. Some may prefer to choose a place that is in the same neighborhood as the person's current home to make sure that the person remains in a familiar surrounding. Others may look for a location that is near the place of residence or work of a caregiver for visiting convenience.

Waiting List

Some residences may have a long waiting list, especially for certain types of accommodation, such as an apartment or a suite. Make sure you ask about the waiting time for your preferred accommodation. This is particularly important if the person needs to move to a retirement residence urgently. Find out what is exactly involved in the admission process: e.g., How long it will take? What paperwork is required? etc.

Levels and Types of Care Services

There can be major differences in the levels and types of personal and health care services available in retirement residences. Some residences may not accept a person with a diagnosis of dementia. Be open and honest about the person's dementia diagnosis. Choose a facility that can accommodate his current, and growing future care and safety needs (see **"How to Make the Right Decision", Page 7**). Higher levels of care are often available in places that have "assisted living" or "dementia care" units. These are usually offered for an extra fee. Other services that might be of interest to you are:

- 24-hour availability of a professional nurse
- medication supervision and administration
- incontinence care
- emergency response services
- added security
- on-site medical clinics

Ask if the person can continue to use his own family physician, if he wishes to do so. Finally, learn about the staff qualifications and numbers, the length of time they have been with the residence, and any special training they may have in caring for persons with dementia.

Certification

In most regions of Canada, retirement residences are not yet regulated by the provincial governments (see **“How to Make the Right Decision”, Page 7**). Some residences are members of self-regulatory organizations. In Ontario, many retirement residences are a member of ORCA, which sets standards of care, inspects, and accredits member homes. ORCA members must meet standards in various areas, such as:

- quality of resident care
- safety and security
- food and meal services
- emergency planning
- building and property maintenance

ORCA can inform you if the residence you are considering is a member in good standing. It also operates a toll-free hotline, funded by the provincial government, called “Retirement Home Complaint Response and Information Service”. You can call this hotline for information about any aspect of retirement living or to receive help in a complaint about any retirement residence (see **“Quick Reference”, Page 38**).

Safety

Persons with dementia are at greater risk for falls, fire and other accidents. Check if the residence is free of obvious safety hazards. Look for the presence of safety features, such as:

- grab bars and non-slip bath surfaces in the bathroom
- safe walking areas inside and outside the residence
- added security (e.g., enclosed gardens, security patrol, alarms, etc.)
- smoke/heat detectors in all rooms/suites
- good lighting

Cost

Often one of the key factors to consider when choosing a retirement residence. There are at least three main costs involved:

- rent for accommodation,
- meals, and
- care services (basic fees as well as extra charges that may apply for supplemental care).

Although the overall cost may be presented to you as a single figure, it is often helpful to ask for a cost break down to see if the service choices you make may lower the cost of living at the residence (e.g., preparing a light meal in one's room, if equipped with a kitchenette). Carefully evaluate the finances of the person to make sure it matches his current and future care needs at the residence (e.g., in case additional care services have to be purchased or the person has to be transferred to a higher level of care within the residence). Some residences may offer subsidized arrangements for residents who are unable to pay the full cost. Contact your local CCAC or the social service office in your region for more information on how to apply for a subsidy. In Ottawa, you can call the City of Ottawa, Supported Living Services at **613-560-0622 (x 26586)**. Finally, make sure you ask the person's family physician to fill in a Disability Tax Credit Certificate to offset some of the costs of his care.

Food Services

The quality of meals is another important characteristic of the residence you should definitely check. Having nutritious meals in a pleasant atmosphere is often one of the main reasons older people may choose to move to a retirement residence. Ask for a copy of the home's meal menu, try their meals (possibly in more than one occasion), and talk to other residents about their satisfaction with the meals. See if the residence has access to a qualified dietician and can accommodate special dietary needs and preferences. Ask if a room service is available, should the person become sick and unable to walk to the common dining area. Ask if there is an extra charge for this service. Having a small kitchen in the room can be a great advantage, if the person is still capable of safely prepare breakfast and light meals. Finally, you may want to check if the dining facilities can accommodate small family dining gatherings and dinner parties.

Social and Recreational Programs

The range of these programs can vary across retirement homes. Look for a residence that has an activity coordinator and offers planned programs of interest to the person. These may include:

- social events
- exercise classes
- bus outings
- games
- therapeutic activities for persons with dementia (e.g., music, pet visiting, gardening, arts and crafts, etc.).

You can ask for a copy of the home's scheduled planned activities. Ask how the residence can facilitate the person's participation in meaningful activities and support family's involvement. If the person has a small pet, look for a pet-friendly residence. Some places welcome small pets, as long as they are well looked after by the resident/family.

Culture and Language

To help the person feel a sense of continuity with his past and to better connect with people in his new home, try to choose a home that can best meet his linguistic, cultural and religious needs. This is especially important if the person belongs to an ethno-cultural minority group and/or is unable to fluently communicate in the official languages.

Some residences may be specialized in caring for persons from a particular ethnic or religious background. Others may have staff members who speak the minority language. Ask about how they can accommodate the person's special needs.

Some persons with dementia may find it overwhelming to participate in the initial process of choosing a small number of residences from a long list of available options. They may prefer delegating this task to their caregivers. But, once a short list of residences has been selected, persons with dementia should visit these places with their caregivers. The participation of the person in choosing his new home will give him a sense of autonomy, choice and control. This can ease some of his anxieties during the process and will help him better adjust after the move.

Contact each residence individually and make an appointment to have a tour and a complementary meal. During the tour explore the ambiance of the residence (general atmosphere and "feel" of the place). After a scheduled visit, you may still choose to drop-in another day at a different time to wander around and get a feel of the place:

- Is it clean, well kept, attractive, bright, welcoming, and homey?
- Do other residents appear to be happy and well cared for?
- Do staff members interact with you, the person with dementia and other residents in a friendly, helpful and respectful manner?
- Does the staff member giving the tour try to learn more about the person and attempt to personalize the tour to meet his needs?
- Does the staff member show interest in and respect to the person, by speaking directly to him and by engaging him in the conversation?
- How flexible and accommodating are the rules, regulations and routines of the residence?



Comments of a family caregiver:

“I wanted something in the neighbourhood so that it would be an area where she could still go to church and people from her Church could come and visit her. A couple of places we looked at they were lovely. But, not her style of living, very posh. We knew people who were here and that it’s warm, friendly and not terribly institutional. The Director of Care went to her house to talk to her as well, just to get to know her a little bit better and see if she felt that this was the appropriate place for her. So, I mean, I was quite impressed with that kind of thing...”

During these visits carefully look at the reaction of the person to the place, other residents and the staff. Persons with dementia often relate to the environment on an emotional level, especially as the disease progresses and their abstract and rational thinking processes become more limited. Besides carefully listening to the person’s verbal comments, pay attention to any changes in his facial expression, mood and behavior. It is important that the person has an overall positive impression of the place. It is quite possible that he will later forget the details of these visits. But, an overall impression of the emotional atmosphere of the residence may stay with him. Knowing that he was directly involved in the choice of his new home can help him better accept the change.



Try to stay for a meal and possibly take part in a social activity at the residence. You can also ask for resident/family references and talk to other residents about their personal experiences. Again, if possible, encourage the person to consider a “short-stay” in the place to have a first hand experience of living in the chosen residence (see “**How to Plan to look for A New Place**”, Page 19).

There are many checklists available to help you prepare for these visits. Here are some examples:

- “*Guide for Selecting a Retirement Residence*” (www.coaottawa.ca; **613-789-3577**)
- “*The Careguide Source for Seniors: Comprehensive Seniors Housing and Services Directory for Eastern and Northern Ontario*” (www.thecareguide.com; **1-800-311-CARE**)
- “*Comprehensive Guide to Retirement Living, Ontario Region*” (www.senioropolis.com; **416-457-6554**)

Choose a checklist and browse it before your visit to the residence to prepare your questions. You can also use the checklist to take notes after the visit. Retirement homes must provide a “Care Home Information Package” which describes the types of accommodation, service availability, and fees. They typically give you the package during the tour. If you wish, you can call and ask for a copy to be mailed to you before your visit. These packages may have pictures of the residence which can help the person better remember the chosen places. You can take your own pictures during the visits to help trigger the person’s memory.

How To Prepare For The Move

You have now chosen a retirement residence and need to get ready for the moving day. Even if you have weeks or months to prepare, it is wise to start planning ahead in order to minimize stress and to have a smooth transition. Many caregivers tend to underestimate the time that is needed to complete all the tasks:

- preparing all documents for the admission
- downsizing and disposing of the belongings that are no longer needed
- packing for the move
- setting up the new accommodation
- cleaning, and possibly renovating and selling the current house

Have reasonable expectations of yourself and the person with dementia. Set a realistic timeline. Make a list of everything that needs to be done and all the people and services that can help you with each specific task. Be sure to include a list of those who should be notified of the change of address. Canada Post has a small booklet, called Smart Moves, which has many tips about moving. It also has services to help with the change of address notification.

Comments of a family caregiver:

“As the move date approaches, I’ll obviously be here more often. I’m fully anticipating that this next couple of weeks is going to be very stressful. Because I’m pretty much going to have to do it all with his assistance, what he wants to pack. But, he can only concentrate or deal with something for a certain period of time and then he just basically has to go and rest. I don’t anticipate it’s going to be any better after he’s moved in. In fact, it will get worse before it gets better, because we have the house renovations.”



The task of downsizing one's belongings from a big house or an apartment to a limited number of items that can fit in a small room or a suite can be both physically and emotionally overwhelming. Persons with dementia often need lots of help from family and friends to complete this task. Most would like to be involved in the process of sorting, packing and distributing their belongings (e.g., decisions about which items to give to family, charity, sell or donate). But, they may not be able to physically and mentally tolerate more than a couple of hours of work at a time. This can significantly slow down the packing and moving process. Be patient, supportive and understanding. Plan ahead as much as you can.

This can be an emotional period for a person with dementia. Many older persons have strong bonds with their household objects and personal belongings. These objects are often a reminder of their life histories, values, interests, connections, and accomplishments. The thought of losing their cherished belongings may provoke mixed feelings. On the one hand, they might feel sad and regret the loss of their valued possessions. On the other hand, they may have a sense of relief from simplifying their lives and letting go of their household objects (and the chores and responsibilities that go with them). Many older persons also welcome the opportunity to give their cherished belongings to their children and other family: "I like to see the smile on their faces while I'm still alive".



Comments of a person with dementia:

"We had some very nice things and we worked very hard to get them. All my life and my husband's we'd say that we wanted this and that and we had to save our money to get that. Right now, I have this dining-room suite. I look at things like that and I think, 'I cannot put a value on it. It was something that happened in my life'. But, now it's time to houseclean. You can't always have everything you want, not at all...."

It is particularly important to encourage a person with dementia to participate in choosing the items to be taken to his new home. These objects should be carefully selected based on their sentimental, functional or even material value. Decorating the person's new accommodation with his personal belongings, can make the place feel more familiar, personalized and homey.

To choose the right items, you need to know exactly how much space is available to you, including any extra storage room that you may have access to. Ask the residence to give you a floor plan of the accommodation with the dimensions, or if the room is vacant measure it yourself.

There are many options for disposing of the belongings that are no longer needed:

- holding a moving sale
- donating to charity
- hiring an auctioneer to sell the items of value in an auction house
- hiring a relocation company to coordinate the entire move for you (i.e., downsizing, disposal, packing, relocation, and set up). Ask if the retirement home can recommend a reputable company.

Plan for the moving day carefully to minimize stress. Some families choose to set up the new accommodation first, before moving the person, to make the move more comfortable for all involved. Postponing the sale of family home or extending the tenancy in a rental unit for an extra month after the person moves to the new residence, can take some of the pressure off. This will allow you to take your time (after you help the person settle into his new home) to gradually empty, clean, renovate, and sell the property.

On the moving day, make sure the residence is notified when to expect the movers in order to allow them to:

- reserve the elevator for the move and make sure it does not conflict with busy meal times
- welcome and receive the person on his arrival
- offer suggestions on how to make him most comfortable (e.g., staying in a guest room until his room is available).

Remember this can be an intense and stressful period for you as well. Do not hesitate to ask for help and share the responsibilities with family/friends and/or paid professional services. Try to block some time for you to relax and recover: e.g., have a quiet time, exercise, get together with family/friends, etc. If you are employed, consider taking a few days off or possibly even talk to your employer to take a paid caregiver leave during this period.

How To Support The Person After The Move

After the move, the person with dementia has to face the challenge of getting used to the changes in his surroundings and daily routine. The person's unique reaction depends on many things, such as:

- his level of memory loss and other changes in his thinking processes
- any other disabilities that he may have (e.g., hearing and visual problems)
- his personality characteristics and lifelong patterns of coping with change
- level of support received from family/friends and the staff of retirement residence

Shortly after moving to a retirement residence, persons with dementia may experience a range of emotions. Some may feel a sense of relief from being in a more protected and supportive environment, and may welcome the opportunity to have more social interaction at the residence. Others may go through a period of grief over the loss of their family home, and the people, places, objects, and activities associated with living at home. They may become sad, withdrawn, irritable or even angry. At times, the anger may be directed toward the caregivers who encouraged them to move.



Comments of a person with dementia:

“Well, you’re not independent anymore, are you? I’m dependent on here for my food. I depend on here for bed to sleep in. It takes a bit of getting used to. It’s just a fact that I’m not in my own home. I like to do my own cooking and cleaning, you miss those sorts of things, going up to the mall every morning. But, I’ve to accept my fate. It was necessary. I’ll get adjusted to it. I’m getting too old to live alone. I was forgetting things....”

Try to be patient, understanding and supportive. Do not discourage the person from talking about his feelings. Accept the person's sense of loss and try to address his concerns the best you can. While you console the person, try to give him hope that with time he will be able to settle into and feel at home in the new place. Focus on the opportunities that the change in residence may bring to the person's life. This can be a time for new experiences, interests and connections.

Persons with dementia can benefit from different types of stimulation often present in a retirement residence:

- social stimulation: e.g., talking with people and participating in social events
- physical stimulation: e.g., going to exercise classes, walking in the hallways, gardening, etc.
- mental stimulation: e.g., participating in games, trivia, arts and crafts, group outings, etc.
- sensory stimulation: e.g., sight of colorful decor, listening to music, pleasant smell of food in the communal dining room, etc.

These types of stimulation can help slow down memory loss.

Be aware that persons with dementia may also experience some unique challenges in this setting. For example, dementia may limit a person's ability to filter information received from the environment. This can lower the person's tolerance of stress and stimulation. This means that the person may become:

- over-stimulated,
- distracted,
- disoriented,
- anxious, and
- tired in the new, more crowded and more demanding environment of a retirement residence (particularly in the first few days or even weeks after the move).

Generally speaking, shortly after the move, many persons with dementia need to have the comfort of continuing with their familiar routines and valued lifestyles. As they feel more at home in their new residence, with time, they may become more open to trying new activities, developing new interests, and making new relationships. Some persons with dementia may have greater difficulty connecting with the staff and other residents. Memory loss and other communication problems they may have can limit their ability to have satisfying social interactions with people at the residence. The following charts present some examples of the ways you can help the person more comfortably settle into his new surroundings.

Orientation, Care, and Comfort

Get to know the staff, especially the person in charge of care services (who is typically the Director of Care). This person can become your main contact for any questions or concerns you might have. Arrange for regular meetings with the Director of Care to discuss the person's care needs.

Learn about the rules, regulations and routines of the residence. Some places have councils or committees that represent residents and families. They can be helpful in orienting you to the place and in answering any questions you may have.

Remember ORCA has a toll-free hotline "Retirement Home Complaint Response and Information Service", in case you have any complaints or need more information on any aspect of retirement living (see **"Quick Reference", Page 38**).

Educate the staff about the person's health, safety, and everyday care needs. This information can help them personalize his care and better meet his needs.

Involve the staff in helping the person develop routines and activity schedules at the residence that are consistent with his preferences and habits.

In the first few days after the move, try to call and visit the person more often and encourage other close family/friends to do so. If you are tired by now and need to take a short break after the move, make sure you ask other close family/friends to have regular contacts with the person during this period (see **Page 37** for tips on how to care for yourself).

During your visits:

- give the person a tour of the residence (you may have to do this on more than one occasion)
- have a meal together
- go for a walk around the building
- possibly join the person in going to a social event at the residence

Ask the staff to remind the person of meal and activity schedules (or even accompany him for the first few times, if needed).

Help the person write a personal activity schedule to keep in his room and check frequently throughout the day.

While encouraging the person to maintain independence in personal care and to take part in activities at the residence, make sure that there are not excessive demands on him that may go beyond his capacity.

Arrange for periods of rest and relaxation (particularly after meals and social activities) to avoid over-stimulation and exhaustion.

Emotional, Social, and Occupational Needs

Be understanding and supportive of the person's emotional needs during this transition. Accept any feelings of loss and grief. Console and reassure the person that he will have the support of family/friends and staff. Try to give him a sense of hope. Focus on the opportunities that the change may bring to his life: new experiences, interests and connections.

To help the staff better relate to the person and to give them topics for conversation with him, prepare a short summary of his life history:

- major life events
- accomplishments
- past occupation and interests
- religious and cultural practices
- likes and dislikes
- hobbies

Make sure staff know of this information and use it.

Talk to the person and the staff to find out how to best support him to feel more connected to the people in his new residence.

Ask the staff if they can assign another resident to act as a temporary buddy for the person to help him navigate the new social terrain. This person can also become a temporary meal time companion.

If the person is reluctant to take part in social events and activities at the residence, find out the underlying causes. Be aware that there may be real barriers the person experiences as a result of the dementia illness and any other disabilities that may exist. Here are a few examples:

- communication problems
- lack of self-confidence and fear of failure
- loss of initiative and motivation
- attention deficits
- lack of physical and mental energy
- difficulty remembering activity schedules

Try to problem solve with the person and the staff to find ways of helping the person choose from and participate in activities that he may enjoy.

Help the person choose activities that are consistent with his life long values, interests, skills and sense of who he is. This can help him feel more comfortable with the activity, have a better chance of succeeding at it, and have fun participating in it.

Many persons with dementia would like to maintain their competence and appreciate the opportunity to perform familiar personal care and everyday domestic tasks, such as:

- doing laundry
- tidying and dusting their room
- preparing a light meal if they have access to a kitchenette and are able to safely do so.

They may also enjoy taking part in activities that mimic their preferred occupational and domestic activities, such as:

- group cooking classes
- gardening
- doing arts and crafts
- playing piano
- doing some suitable volunteer work at the residence

Remind and prompt the person to go to the chosen activities or ask the staff to do so. Mark them on the activity calendar or a personal daily schedule. Occasionally, join the person in going to some of the social events at the residence.

Besides helping the person make new connections with the people inside the residence, support him to keep his links with the outside community as well. Going out with family/friends can help the person maintain a sense of continuity with the past and feel connected with the outside world.

For many older persons the most enjoyable social activity is getting together with close family/friends. The love and attention you and other family/friends can give the person can be a great reassurance to him during this transition. Because long term memory is often retained much longer than short term memory, persons with dementia can particularly enjoy talking about their life stories and past memories. Looking at family photo albums together can often trigger such memories.

You have gone through an intense period of helping a person with dementia make important decisions and go through a challenging transition. As a caregiver, it is very important that you pay attention to your own physical and emotional needs as well. After the move, just like the person you are caring for, you may also experience mixed feelings. On the one hand, you may have a sense of relief from knowing that the person is finally in a more protected and supportive environment, and that you have fewer day to day responsibilities. On the other hand, you may also go through a period of grief. For example, you may:

- experience a sense of loss
- question your decisions
- feel sad, guilty, angry or resentful

You may feel angry at:

- the person with dementia (particularly, if he has difficulty accepting the new realities and adjusting to the change)
- other involved family/friends (if you believe that they did not carry out their fair share of responsibilities)
- professional service providers (if you feel that they failed to give you the guidance, information and support you needed).

You may also physically feel tired and run down.

The following charts present some examples of the ways you can help the person more comfortably settle into his new surroundings.

Comments of a family caregiver:

“The first two weeks she had nostalgia, she missed her home. She had even by-passed the previous one and gone back to her home in London, feeling of being lost in this new place. It took about two weeks for her to have this transition. I’d say she’s more happy here. She has two other ladies that sit at her table and look out for her. Every day, there’s exercise class and they tell me now that she’s going to that. She had a great time at the sugar bush. Of course, the next day she had forgotten that she had been there. I’ve even seen she had some lipstick on today, for the first time....”

- Do not ignore your personal needs and feelings.
- Find sources of comfort and support for yourself.
- Ask family/friends and professional providers for practical help and guidance.
- Talk about your feelings and experiences with trusted friends/family or a professional counselor, as appropriate. Contact your local CCAC and/or the Alzheimer Society for more information on the support services available in your region (see **“Quick Reference”, Page 38**).
- Be patient and hopeful. As the person settles into his new home, you will have fewer worries and responsibilities. With time, you may find that you can spend more quality time with the person, enjoy your visits more, and even notice positive changes in your relationship.
- You may take comfort in seeing some improvements in the person’s physical and mental health, such as:
 - eating and sleeping better
 - gaining weight
 - being more social, alert and interactive
 - experiencing fewer medical emergencies



Agencies/Organizations Mentioned In This Guide

The Alzheimer Society

The Alzheimer Society works to improve the quality of life for Canadians affected by Alzheimer's disease and other dementias. It is located in over 140 communities across every province of Canada. It helps persons with dementia and their caregivers through a number of services, including:

- giving information and education to people with dementia, caregivers, physicians, and other health care providers
- connecting persons with dementia and their caregivers to support groups and services to help them understand the disease, share their feelings and to plan for the future
- providing resources in print, video and audio (some of which are designed specifically for people with dementia)
- offering Home Safety and Alzheimer Wandering Registry

Contact the Alzheimer Society of Canada for more information and to find the Society in your community (visit website www.alzheimer.ca or call **1-800-616-8816**). In Ottawa, contact the Alzheimer Society of Ottawa and Renfrew County (visit website www.alzheimer-ottawa-rc.org or call **613-523-4004**).

Community Care Access Centres

In Ontario, the Ministry of Health funds the Community Care Access Centres to:

- give information and refer to various community support services and programs
- assess eligibility and coordinate publicly funded home care services
- assess eligibility and arrange admissions to long term care homes when community care is no longer appropriate

Visit website www.ccac-ont.ca or call **416-310-CCAC** to find the closest CCAC to you. In Ottawa, contact Champlain CCAC (www.champlain.ccac-ont.ca ; **613-745-5525**).

Non-Profit Community Support Service Agencies

In Ontario, these are non-profit agencies that provide a range of services to help older persons remain in their homes. Each agency serves a specific geographic area. Paid workers and volunteers supported by professional staff, provide a variety of volunteer programs and for fee services at reasonable cost (or a sliding payment scale). Services include:

- homemaking and home help services: e.g., light housekeeping, sitter/personal care, respite care, etc.
- home maintenance and repair services: e.g., minor household repairs, snow shoveling, yard work, odd jobs, etc.
- transportation services: e.g., volunteer drivers getting seniors to medical appointments, grocery bus, etc.
- volunteer friendly visiting and telephone reassurance programs for isolated seniors
- social, recreational and cultural programs: e.g., drop-in leisure centres, exercise programs, organized group outings, day centre programs for frail older adults, etc.
- Professional services: e.g., physiotherapy and occupational therapy, foot care, counseling, etc.
- Meal services: e.g., Meals on Wheels (home-delivered meals to seniors), Wheels to Meals (transportation for frail seniors to senior centres for a hot meal and social programs), luncheon programs, etc.

In Ottawa, to find out which community support agency services your area, visit the Ottawa Community Support Coalition website: www.communitysupportottawa.ca. In other regions of Ontario, call your local CCAC for more information (see above).

Ontario Ministry of the Attorney General Office of the Public Guardian and Trustee

This office safeguards the legal, personal and financial interests of adults who are incapable of managing their own affairs. It investigates situations when an individual may be incapable and at risk of suffering serious financial or personal harm. It may also act as a decision maker of last resort for treatment and long term care admission decisions for individuals who have no one else to do so. The office's website provides information on:

- assigning a Power of Attorney
- capacity assessment
- substitute health care and financial decision making
- role of the Public Guardian as a decision-maker

For more information visit Ontario Ministry of the Attorney general website at www.attorneygeneral.jus.gov.on.ca or call **1-800-891-0506**. In Ottawa, call **613-241-1202**.

Ontario Retirement Communities Association

This is a non-profit and self-regulatory organization which sets standards of care, inspects, and accredits member retirement homes. Members must meet standards in various areas, such as:

- quality of resident care
- safety and security
- food and meal services
- emergency planning
- building and property maintenance

ORCA can inform you if the residence you are considering is a member in good standing. It also operates a toll-free hotline, which is funded by the provincial government, called “Retirement Home Complaint Response and Information Service”. You can call this hotline for information about any aspect of retirement living or to receive help in a complaint about any retirement residence.

For more information, visit ORCA website at www.orca-homes.com or call **1-800-361-7254**.

Specialized Geriatric Services

Regional Geriatric Programs

In Ontario, these are networks of specialized assessment, treatment and rehabilitation services for older persons who have complex health and social problems. These programs work closely with family physicians and other health care providers to meet the needs of frail and vulnerable seniors and their caregivers. In Ottawa, older persons referred to the program will receive a screening assessment in their own homes. As appropriate, they may then be referred to other services within the program, such as a geriatric day hospital program or an in-patient unit in a hospital.

Visit the website of Regional Geriatric Programs of Ontario for more information and to find the program in your area (www.rgps.on.ca). In Ottawa, contact Regional Geriatric Program of Eastern Ontario (visit website www.rgpeo.com or call **613-562-6262** if you live East of Bronson Avenue and the Rideau River in the South End or call **613-721-0041** if you live in the west region of Ottawa).

Geriatric Psychiatry Community Services of Ottawa

This program provides services to older persons with dementia and other types of mental health problems. The services include:

- outreach mental health assessment
- consultations with a geriatric psychiatrist
- on-going counseling, support and education
- personal-property capacity assessment

For more information, call **613-562-9777**.

Resources Mentioned In This Guide

At Home with Alzheimer Disease: Useful Adaptations to the Home Environment (visit the Canada Mortgage and Housing Corporation website www.cmhc.ca or call **1-800-668-2642**)

Communicating in Print with/about Seniors (1991). Government of Canada, Minister of Supply and Services (visit website <http://openlibrary.org/b/OL18235245M/Communicating-in-print-with/about-seniors>)

Comprehensive Guide to Retirement Living, Ontario Region (visit website www.senioropolis.com or call **416-457-6554**)

Directory of Housing and Residences for Seniors in Ottawa (visit the Council on Aging of Ottawa website www.coaottawa.ca or call **613-789-3577**)

Directory of Resources for Senior Citizens of Ottawa (visit the Senior Citizen Council of Ottawa website www.seniorcouncil.org or call **613-234-8044**)

Guide for Selecting a Retirement Residence (visit the Council on Aging of Ottawa website www.coaottawa.ca or call **613-789-3577**)

The Careguide Source for Seniors: Comprehensive Seniors Housing and Services Directory for Eastern and Northern Ontario (visit website www.thecareguide.com or call **1-800-311-CARE**)

When Home is no Longer an Option: A journey of Acknowledging, Adapting, Adjusting, and Accepting (visit the Alzheimer Society of Ottawa and Renfrew County website www.alzheimer-ottawa-rc.org or call **613-523-4004**)

Was This Guide Helpful?

We would appreciate your opinion on the usefulness of this guide for future revisions. Please take a few minutes to answer the following questions:

Did you use this guide as (please check):

- Caregiver of a person with dementia
- Caregiver of an older person without dementia
- Older person considering a move to a retirement residence
- Professional service provider. Please specify your background.....
- Other: please specify.....

On a scale of 1 (not useful at all) to 5 (very useful), how useful was this guide to you? Please circle the number of your choice: 1 2 3 4 5

What did you like most about this guide?.....
.....
.....

What did you like least about this guide?
.....
.....

What can we do to improve this guide?.....
.....
.....

Where did you get this guide?.....

Other comments:.....
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Thank you for your help. Please return the completed form by mail or fax to:

Regional Geriatric Program of Eastern Ontario
RGP Administration – Box 678
The Ottawa Hospital, Civic Campus
1053 Carling Avenue, Ottawa, ON, K1Y 4E9
Tel: **613-761-4458** Fax: **613-761-5334**







TO RETIREMENT HOME

*A Guide for Caregivers of Persons with
Dementia*

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www.rgpeo.com

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