



Making Choices:

Care at Home or Admission to a Care Facility

Decision Aid for Family Members of Persons with Dementia

University of Ottawa

Decision Aid Development Team

Janet Allan RN MScN

Carole Comeau RN MScN

Malcolm Hing MD MSc FRCP(C)

Susan Mitchell MD MPH FRCP(C)

Annette O'Connor RN PhD

Acknowledgments

Christine Bradley MSW

Lynne Delorme RN BScN

Nancy Edwards RN PhD

Valerie Fiset RN MScN

Laurie Ann Glenn RN MHA

Angèle Lavallée RN

Hilary Kemsley MSW

Jo Logan RN PhD

Pierrette Papai RN PhD

Margaret Ross RN PhD

Ottawa Health Decision Centre
Clinical Epidemiology Program
Ottawa Health Research Institute
The Ottawa Hospital, Civic Campus
1053 Carling Ave.,
Ottawa, ON K1Y 4E9
Phone: 613 761-5499
Fax: 613 761-5492
E-mail: ldrake@ohri.ca

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Welcome!

This workbook will lead you through the steps needed to make an informed choice between two care options. It is specifically designed to help you decide whether your relative with dementia should receive care at home or be admitted to a long-term care facility.

Instructions

1. Set aside 30-45 minutes.
2. Have a pencil ready.
3. Work through each section of the workbook. Follow the instructions as you go. Check or write your comments in the spaces provided.
4. Upon completion, discuss your reactions to the workbook with a health care professional such as a physician, nurse or social worker involved in your relative's care. Staff from your local Community Care Access Centre (CCAC) can also provide you with the assistance needed to further explore the options presented.

Please Note:

Research studies that support some of the information presented are referenced by number at the back of the workbook.

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This Workbook is for You If...

- you are responsible for a relative with dementia who is unable to make decisions about their own personal care
- you are considering whether your relative should remain at home or be admitted to a long-term care facility
- you are uncertain about which option to choose

You Will Learn About...

- dementia and how it affects you and your relative
- ways to cope with the effects of dementia
- the advantages and disadvantages of receiving care at home or in a long-term care facility
- the steps to decision making

What is Dementia? ^(1,2,3)

Dementia is a term used to describe a group of symptoms. Symptoms commonly included in that group are:

- loss in memory, judgement and reasoning, and;
- changes in mood or behaviour

The Most Common Causes of Dementia are:

- Alzheimer Disease

This disease is characterized by the slow destruction of cells in the brain.

Persons with Alzheimer Disease show a steady decline in mental ability over a number of years.

- Vascular Dementia

This condition occurs when multiple pinpoint size strokes take place deep in the brain. Persons with vascular dementia may show a sudden decline in mental ability followed by a period of stability.

The vast majority of persons with dementia cannot be cured

How Does Dementia Affect your Relative?

Persons with dementia experience problems which interfere with their ability to perform routine activities^(4, 5, 6). Please check the problems that have affected your relative in the last six months.

Thinking

- Forgetful
- Unable to organize themselves
- Unable to recognize familiar people
- Unable to name familiar objects
- Unable to understand consequences of actions
- Unable to handle money or finances



Emotions

- Easily frightened
- Anxious
- Depressed
- Agitated especially in unfamiliar situations
- Does not respond when spoken to
- Unpredictable mood swings



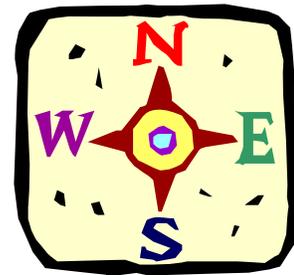
Daily Activities

- Unable to use the phone
- Unable to prepare meals
- Unable to do routine household chores
- Unable to do shopping
- Has problems driving a car
- Needs assistance with personal care
- Needs supervision at meal time or won't eat
- Doesn't remember to use the bathroom



Challenging Behaviours

- Repetitive behaviour
- Paces in the house
- Wanders outdoor and doesn't know how to return home
- Verbally and/or physically aggressive at times
- Inappropriate sexual behaviour
- Uncooperative
- Doesn't sleep well at night



Other Problems...

Is your relative with dementia experiencing any other problems?

How Does Dementia Affect You?

Being responsible for a relative with dementia also affects your life. Here are some of the difficulties people in your situation have reported (^{7, 8, 9}). Please check the things that have affected you in the last six months.

Physical

- Lack of sleep
- Increased fatigue
- Changes in appetite
- Worsening of existing health problems
- Other

Emotional

- Worried
- Frustrated
- Feeling sad
- Feeling guilty
- Feeling powerless
- Feeling resentful
- Feeling overwhelmed
- Other

Social

- Less contact with friends
- Attend fewer activities outside the home
- Problems juggling work and care responsibilities
- Feeling lonely
- Can't travel or take vacations
- Other



Financial and Legal Responsibilities

- Difficulty sorting out finances
- Having trouble making ends meet
- Struggling with making decisions on behalf of your relative
- Other

Other Difficulties...

Is being responsible for a relative with dementia affecting your life in any other way?

How Do You Cope with the Effects of Dementia?

There are a number of things people do to cope with the effects of dementia (^{10, 11, 12}).

Please check those that apply to your situation.

Ways to Maintain Your Well-Being...

- I accept help when offered
- I seek help when needed
- I am a member of a support group
- I regularly set aside time for myself
- I maintain close relationships with important people in my life
- I socialize with my friends
- I remember to laugh
- I gain strength and security from my religious beliefs
- I see a health care professional when needed

Ways to Maintain Your Relative's Well-Being...

- I ensure that my relative's home environment is as safe as possible
- I make sure that my relative's daily care needs are met
- I ensure that leisure and recreational activities are available for my relative
- I involve health care professionals in the on-going care of my relative

Options for Persons with Dementia

The care needs of your relative with dementia may increase over time. Therefore, suitable plans have to be made to respond to those needs. The following two options should be considered when making such plans:

Option 1

Care at Home



Option 2

Admission to a Long-term Care Facility



Let's examine the advantages and disadvantages of each option....

Option 1: Care at Home

A range of in-home and community services is available to persons with dementia who wish to remain at home. These services are primarily accessible through your local Community Care Access Centre (CCAC). Services frequently used by persons with dementia are listed below:

Type of Service	Description	Service Limits
Nursing Services	Assistance at home with health problems from qualified nursing staff	Up to 2 visits per day, based on assessed needs
Personal Support Services/Homemaking	Assistance at home with personal hygiene and routine activities of daily living	Up to 60 hours per month, based on assessed needs
Therapy Services	In-home physio, speech and occupational therapy to promote independence	Based on assessed needs
Dietetic Services	In-home nutritional counselling	Based on assessed needs
Social Work Services	In-home counselling and support for caregivers	Based on assessed needs
Home Delivered Meal Services	Provide hot noon meal at home	Delivered Monday to Friday
Caregiver Respite Services	Provide a few hours per week of in-home relief to primary caregiver	Usually provided within the Personal Support Homemaking limits
Adult Day Away Programs	Provide supervised group activities outside the home	Up to 2 days per week (overnight service also available)
Short-Stay Programs	Short-term admission to a nursing home or a home for the aged.	Up to 90 days per year (minimum 1 week but no more than 30 consecutive days per stay)

Determination of Eligibility

Call your local CCAC to request an assessment. Someone will contact you and your relative to determine eligibility and assess service needs.

How Much Does it Cost?

All the services listed are covered by the Ontario Health Insurance Program and are provided at no cost except for the Home Delivered Meal Services, Adult Day Away Programs and Short-Stay Programs. Most Home Delivered Meal Services charge about \$7 per meal. Adult Day Away Programs charge between \$10 and \$30 per day, including lunch. Short-Stay Programs charge approximately \$32 per day. Note that some people choose to purchase additional services to supplement those covered by the Ontario Health Insurance Program.

Possible Advantages and Disadvantages of Care at Home ^(13, 14, 15, 16):

Advantages

- care and services can be delivered in the privacy of the home
- personalized care
- easier to monitor the quality of care provided
- surrounded by personal belongings and pet(s)
- family and/or friends are nearby

Disadvantages

- the home may not be safe and secure
- amount of services available not always sufficient to meet needs
- daily routine revolves around the schedule of service providers
- many care giving tasks remain the responsibility of the family
- family and/or friends are not always available

Option 2: Admission to a Long-term Care Facility

In this workbook, the words “long-term care facility” include settings such as retirement homes, nursing homes, and homes for the aged.

Retirement Homes

Retirement homes are not regulated by the provincial government. Although some facilities offer services similar to those found in nursing homes and homes for the aged, most retirement homes cannot admit persons who require a high level of care.

Nursing Homes and Homes for the Aged

These facilities are regulated by the provincial government and must offer:

- nursing and personal care on a 24-hour basis under the supervision of a registered nurse or a registered practical nurse.
- medical care on a visitation basis and assistance with medications
- regular meal services to accommodate a variety of diets
- therapy services such as physiotherapy and occupational therapy
- recreational, spiritual and social programs
- regular laundry and housekeeping services

Request for Admission

Admission to a retirement home is handled by the home itself and can only occur if your relative consents to it. Ability to pay and availability of the needed services also determine whether admission is possible. Admission to a nursing home or a home for the aged is coordinated by your local Community Care Access Centre (CCAC). Consent to admission can be given by you on your relative’s behalf if the person is found incapable of making such a decision. Call the CCAC to begin the process of determining your relative’s eligibility for admission to a long term care facility.

How Much Does it Cost?

Retirement homes are not subsidized by the government. Therefore, the resident must pay for all the services requested as well as for the accommodation charges. These charges vary greatly from one retirement home to another and usually range between \$1500 and \$5000 per month.

Nursing homes and homes for the aged are subsidized by the Ontario Ministry of Health. That is, care and services offered in these facilities are paid by the government. The resident only pays for the accommodation charges. This “co-payment” is set by the Ministry and is the same for all nursing homes and homes for the aged. It is based on the type of accommodation requested (basic, semi-private or private) and ranges between \$1500 and \$2100 per month. A reduced rate is available for residents who cannot afford the cost of basic accommodation. In fact, depending on the resident’s income, the cost of basic accommodation can be reduced by up to \$400 per month.

Possible Advantages and Disadvantages of Admission to a Long-term Care Facility ^(17, 18, 19):

Advantages

- staff available on a 24-hour basis
- supervised environment to ensure safety and security
- services to meet physical, emotional and social needs
- physician visits regularly
- relief from most care giving responsibilities

Disadvantages

- getting to the facility for visits may be difficult
- less control over the quality care provided
- less personalized care
- lack of privacy
- minimal amount of personal belongings permitted and pets are rarely allowed

Steps to Decision Making

When deciding for a relative with dementia who is unable to make a decision with regard to admission to a nursing home or a home for the aged ⁽²⁰⁾:

- **Respect the previously expressed wishes of the person**

Has your relative ever expressed verbally or in writing, when he or she was able to make such decision, where he or she wished to be cared for in these circumstances?

If his or her wish is not known or it is no longer feasible to follow the wish...

- **Consider the values and beliefs held by the person**

Given the values and beliefs held by your relative when he or she was able to make such decision, where do you think he or she would want to be cared for under these circumstances?

And...

- **Act in the person's best interests**

Given your relative's needs and the current care giving situation, which option is likely to provide the best possible quality of life?

Follow the steps listed below when you are ready to decide whether your relative with dementia should receive care at home or be admitted to a long-term care facility:

Step 1

Given my relative's needs and the current care giving situation, what are the most important advantages and disadvantages associated with care at home and admission to a long-term care facility?

Step 2

Where would my relative want to be cared for under the present circumstances?
Is this wish still feasible?

Step 3

How is this decision affecting me?

Step 4

When does the decision have to be made?

Step 5

What questions need to be answered before deciding?

Step 6

What is my overall "leaning" when considering the options presented?

What Have Other People Like You Decided?

In the next pages, you will find out how people like you have used the workbook.

Helen and her Husband

Step 1 Given my husband's needs and the current care giving situation, what are the most important advantages and disadvantages associated with care at home and admission to a long-term care facility?

Care at Home

Advantages

- care and services in the privacy of the home
- personalized care
- easier to monitor quality of care
- surrounded by personal belongings and pet(s)
- family and/or friends are nearby
- We can be together**

Disadvantages

- home may not be safe and secure
- amount of services available not always sufficient to meet needs
- daily routine revolves around the schedule of service providers
- many care giving tasks remain the responsibility of the family
- family and/or friends are not always available
- Different people all the time, no consistency**

Admission to a Long-Term Care Facility

Advantages

- staff available on a 24-hour basis
- supervised environment to ensure safety and security
- services to meet most needs
- physician visits regularly
- relief from most care giving responsibilities

Disadvantages

- getting to the facility for visit may be difficult
- less control over the quality of care provided
- less personalized care
- lack of privacy
- minimal amount of personal belongings permitted and pets are rarely allowed

Step 2 Where would my husband want to be cared for under the present circumstances? Is this wish still feasible?

Knowing my husband, I think he would want to stay at home. I can still take care of him.

Step 3 How is this decision affecting me?

Taking care of my husband provides me great joy. I want to do it as long as possible. Beside, I don't see how I could manage on my pension alone...

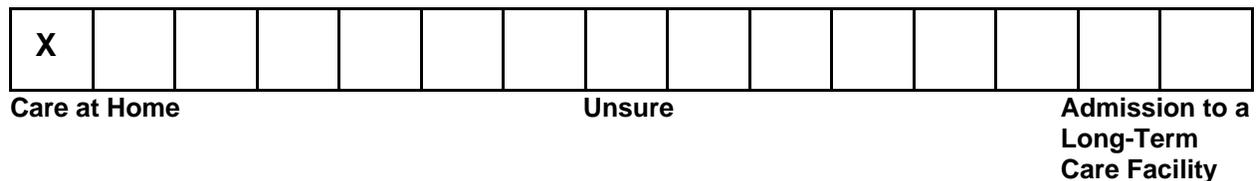
Step 4 When does the decision have to be made?

- In less than one month
- In more than a month but in less than six months
- More than 6 months
- I'm not sure

Step 5 My questions

I'm managing well now...but if someone must come to our house, could it be the same person all the time?

Step 6 My leaning



Frank and his Aunt

Step 1 Given my aunt's needs and the current care giving situation, what are the most important advantages and disadvantages associated with care at home and admission to a care facility?

Care at Home

Advantages

- care and services in the privacy of the home
 - personalized care
 - easier to monitor quality of care
 - surrounded by personal belongings and pet(s)
 - family and/or friends are nearby
-
-

Disadvantages

- home may not be safe and secure
 - amount of services available not always sufficient to meet needs
 - daily routine revolves around the schedule of service providers
 - many care giving tasks remain the responsibility of the family
 - family and/or friends are not always available
-
-

Admission to a Long-term Care Facility

Advantages

- staff available on a 24-hour basis
 - supervised environment to ensure safety and security
 - services to meet most needs
 - physician visits regularly
 - relief from most care giving responsibilities
-
-

Disadvantages

- getting to the facility for visits may be difficult
 - less control over the quality of care provided
 - less personalized care
 - lack of privacy
 - minimal amount of personal belongings permitted and pets are rarely allowed
-
-

Step 2 Where would my aunt want to be cared for under the present circumstances? Is this wish still feasible?

My aunt used to say that she didn't want to go to a nursing home. I'm respecting her wishes...but as the disease progresses, her care needs increase and she can no longer cope at home on her own. She refused all the assistance offered. Her quality of life is decreasing rapidly...

Step 3 How is this decision affecting me?

I feel awful! I don't know what to do. I'm so confused!

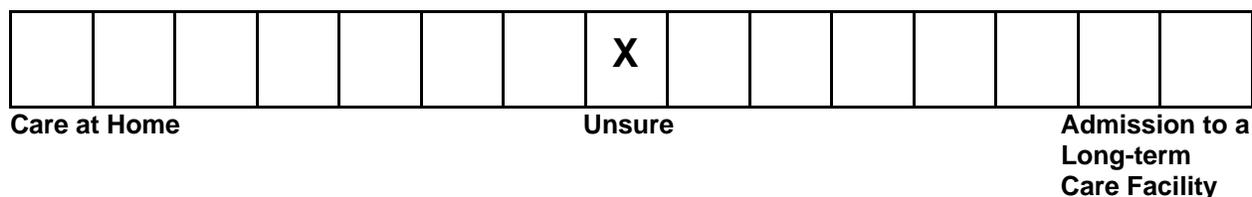
Step 4 When does the decision have to be made?

- In less than one month
- In more than a month but in less than six months
- More than 6 months
- I'm not sure

Step 5 My questions

Can my aunt come back home if she doesn't like living in a care facility ?

Step 6 My leaning



Margaret and her Mother

Step 1 Given my mother's needs and the current care giving situation, what are the most important advantages and disadvantages associated with care at home and admission to a care facility?

Care at Home

Advantages

- care and services in the privacy of the home
 - personalized care
 - easier to monitor quality of care
 - surrounded by personal belongings and pet(s)
 - family and/or friends are nearby
-
-

Disadvantages

- home may not be safe and secure
- amount of services available not always sufficient to meet needs
- daily routine revolves around the schedule of service providers
- many care giving tasks remain the responsibility of the family
- family and/or friends are not always available
- Additional services have to be purchased...costly**

Admission to a Long-term Care Facility

Advantages

- staff available on a 24-hour basis
- supervised environment to ensure safety and security
- services to meet most needs
- physician visits regularly
- relief from most care giving responsibilities
- More time with my kids and husband**

Disadvantages

- getting to the facility for visits may be difficult
 - less control over the quality of care provided
 - less personalized care
 - lack of privacy
 - minimal amount of personal belongings permitted and pets are rarely allowed
-
-

Your Decision

Now, it's your turn to decide....

Step 1 Given my relative's needs and the current care giving situation, what are the most important advantages and disadvantages associated with care at home and admission to a long-term care facility?

Care at Home

Advantages

- care and services in the privacy of the home
 - personalized care
 - easier to monitor quality of care
 - surrounded by personal belongings and pet(s)
 - family and/or friends are nearby
-
-

Disadvantages

- home may not be safe and secure
 - amount of services available not always sufficient to meet needs
 - daily routine revolves around the schedule of service providers
 - many care giving tasks remain the responsibility of the family
 - family and/or friends are not always available
-
-

Admission to a Long-Term Care Facility

Advantages

- staff available on a 24-hour basis
 - supervised environment to ensure safety and security
 - services to meet most needs
 - physician visits regularly
 - relief from most care giving responsibilities
-
-

Disadvantages

- getting to the facility for visits may be difficult
 - less control over the quality of care provided
 - less personalized care
 - lack of privacy
 - minimal amount of personal belongings permitted and pets are rarely allowed
-
-

Step 2 Where would my relative want to be cared for under the present circumstances? Is this wish still feasible?

Step 3 How is this decision affecting me?

Step 4 When does the decision have to be made?

- In less than one month
- In more than a month but in less than six months
- More than 6 months
- I'm not sure

Step 5 My questions

Step 6 My leaning

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Care at Home

Unsure

Admission to a
Long-term
Care Facility

Suggested Readings

Alzheimer Society of Canada. (1991). Alzheimer Disease: A handbook for care. Toronto, ON: Author.

Council on Aging of Ottawa-Carleton. (1991). Guide for selecting a long term care facility. Ottawa, ON: Author.

Howard, J., Monticone, G. T., Meadus, J. E., Wahl, J. A., Webb, G., Chrolavicius, R. A., Colvin, L. & Chernin, S. (1998). Long term care facilities in Ontario: The advocate's manual. Toronto, ON: The Advocacy Centre for the Elderly.

Regional Municipality of Ottawa-Carleton. (1997). Directory of housing and residences for seniors in Ottawa-Carleton. Ottawa, ON: Homes for the Aged Department.

Senior Citizens Council of Ottawa-Carleton. (1999). Directory of resources for senior citizens of Ottawa-Carleton. Ottawa, ON: Author.

Other Resources

Ottawa-Carleton Community Care
Access Centre (CCAC)
4200 Labelle St.,
Gloucester, ON
K1J 1J8
(613) 745-5525

Ministry of Health and Long Term Care
Health Care Programs
Eastern Region, Ottawa Office
310- 47 Clarence Street,
Ottawa, ON
K1N 9K1
(613) 241- 4263

Alzheimer Society of Ottawa-Carleton
1750 Russell Road
Ottawa, Ontario
K1G 5Z6
(613) 722-1424

Office of the Public Guardian and
Trustee, Ottawa Office
244 Rideau Street, 3rd floor
Ottawa, ON
K1N 5Y3
(613) 241-1202

Advocacy Centre for the Elderly
701- 2 Carlton Street
Toronto, ON
M5B 1J3
(416) 598-2656

Scientific References

1. American Psychiatric Association (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author.
2. U.S. Department of Health and Human Services (1996). Recognition and initial assessment of Alzheimer's disease and related dementias. AHCPH Publication No. 97-0702. Rockville, MD: Author.
3. Patterson, C., Gauthier, S., Bergman, H., Cohen, C. A., Feightner, J. W., Feldman, H., & Hogan, D. B. (1999). The recognition, assessment and management of dementing disorders: Conclusions from the Canadian Consensus Conference on Dementia. Canadian Medical Association Journal, 160(12 Suppl).
4. Reisberg, B, Ferris, S. & De Leon, M. (1982). The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 139 (9), 1136-1139.
5. Davis, L., Buckwalter, K. & Burgio, L. (1997). Measuring problem behaviors in dementia: Developing a methodological agenda. Advances in Nursing Science, 20 (1), 40-55.
6. McDougall, G. (1995). A critical review of research on cognitive functional impairment in older adults. Archives of Psychiatric Nursing, 9 (1), 22-33.
7. Canadian Study of Health and Aging (1994). Patterns of caring for people with dementia in Canada. Canadian Journal on Aging, 13(4), 470-487.
8. Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S. & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. The Gerontologist, 31(4), 483-489.
9. Pratt, C, Wright, S. & Shmall, V. (1987). Burden, coping and health status: A comparison of family caregivers to community dwelling and institutionalized Alzheimer's patients. Journal of Social Work, 10, 99-112.

10. Bowd, A. D. & Loos, C. H. (1996). Needs, morale and coping strategies of caregivers for persons with Alzheimer's disease in isolated communities in Canada. American Journal of Alzheimer's Disease, 32-39.
11. Buffman, M. D. & Brod, M. (1998). Humour and well-being in spouse of patients with Alzheimer's disease. Applied Nursing Research, 11(1), 12-18.
12. Lach, H. W., Reed, T., Smith, J. & Carr, D. B. (1995). Alzheimer's disease: Assessing safety problems in the home. Geriatric Nursing, 16(5), 160-164.
13. McCullough, L. B. Wilson, N. L., Teasdale, T. A., Kolpakchi, A. L. & Skelly, J. R. (1993). Mapping personal, familial, and professional values in long term care decisions. The Gerontologist, 33(3), 324-332.
14. Guberman, N., Maheu, P. & Maillé, C. (1992). Women as family caregivers: Why do they care? The Gerontologist, 32(5), 607-617.
15. Collins, C., King, S. & Kokinakis, C. (1994). Community services issues before nursing home placement of persons with dementia. Western Journal of Nursing Research, 16(1), 40-56.
16. Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. Research on Aging, 7(3), 329-361.
17. Bowers, B. J. (1988). Family perceptions of care in a nursing home. The Gerontologist, 28(3), 361-368.
18. Ross, M. M., Rosenthal, C. J. & Dawson, P. (1997). Patterns of caregiving following the institutionalization of elderly husbands. Canadian Journal of Nursing Research, 29(2), 79-98.
19. Gold, P. D., Reis, M. F., Markiewicz, D. & Andres, D. (1995). When home caregiving ends: A longitudinal study of outcomes for caregivers of relatives with dementia. Journal of the American Geriatrics Society, 43(1), 10-16.
20. Health Care Consent Act, S.O.1996, C. C.2, s. 42.