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**Development and Evaluation of a Decision Aid  
for Family Members Considering  
Long-Term Care Options for a Relative With Dementia**

By

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**Thesis submitted to the School of Graduate Studies and Research  
in partial fulfilment of the requirements for the degree of  
Master of Science in Nursing**

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## Abstract

**Objective.** *To evaluate the effectiveness of a decision aid developed specifically for family members considering whether or not their relative with dementia should be admitted to a care facility.*

**Design.** *One-group non-randomized before and after study.*

**Setting.** *Ottawa-Carleton, Ontario, Canada.*

**Participants.** *Convenience sample of 27 family members responsible for making care decisions on behalf of a relative with dementia living at home.*

**Intervention.** *Family members completed a self-administered decision aid fashioned as a workbook to learn about long-term care options available to persons with dementia.*

**Main Outcome Measures.** *Decisional conflict (uncertainty about which course of action to take), knowledge of long-term care options, stages of change (pre-contemplation, contemplation, preparation, action and maintenance), choice predisposition (care at home versus admission to a care facility) as well as satisfaction with the decision aid and the decision making process.*

**Results.** *After using the decision aid, family members had a significant reduction in decisional conflict and a significant increase in knowledge. The decision aid had a minimal effect on choice predisposition and appeared to be more useful to those in the contemplation stage. Generally, family members were satisfied with the decision aid but felt it was less successful at preparing them to make a better decision, to organize their thoughts, to look at the wishes of their relative with dementia, and to communicate their opinion about the options. Nevertheless, the majority reported that they would definitely recommend the decision aid to other family members facing the same decision.*

**Conclusions.** *The decision aid shows promise in helping family members of persons with dementia make decisions about location of care.*

## **Acknowledgments**

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**Contents**

---

**Abstract / ii**

**Acknowledgements / iii**

**Contents / iv**

**List of Tables / vi**

**List of Figures / vii**

**Introduction / 1**

**1. Review of Previous Research / 4**

**Decision Support Needs / 4**

**Decision Support Interventions / 7**

**Objectives and Hypotheses / 10**

**Conceptual Framework / 10**

**2. The Decision Aid / 18**

**Development of the Decision Aid / 18**

**Content and Format / 19**

**3. Research Methods / 20**

**Research Design / 20**

**Sample / 21**

**Data Collection Procedures / 21**

**Evaluation Measures / 22**

**Data Analysis / 25**

**4. Results / 27**

**Recruitment of Participants / 27**

**Characteristics of Participants and their Relative with Dementia / 28**

**Decisional Conflict / 31**

**Knowledge / 31**

**Stages of Change / 34**

**Choice Predisposition / 37**

**Satisfaction / 37**

**5. Discussion / 40**

**Limitations / 44**

**Implications for Nursing / 45**

**Future Research / 47**

**Conclusion / 48**

**References / 49**

**Appendix A: Making Choices: Care at Home or in a Care Facility  
A Decision Aid for Family Members of Persons with Dementia / 61**

**Appendix B: Eligibility Screening Tool / 62**

**Appendix C: Consent Form / 63**

**Appendix D: Baseline Questionnaire / 64**

**Appendix E: Post-Questionnaire / 65**

**List of Tables**

---

- 1. Determinants of Decision According to the Ottawa Decision Support Framework / 13**
- 2. Characteristics of Family Members (n=27) / 29**
- 3. Characteristics of Persons with Dementia (n=27) / 30**
- 4. Changes in Decisional Conflict (n=27) / 32**
- 5. Changes in Knowledge Test Scores (n=27) / 33**
- 6. Comparison of Five Variables Across the Stages of Change / 35**
- 7. Satisfaction of Family Members at Post-Intervention (n=27) / 38**

**List of Figures**

---

1. **The Ottawa Decision Support Framework / 11**
2. **The Transtheoretical Model / 15**
3. **One-Group Non-Randomized Before and After Design / 20**
4. **Flow of Study Participants / 27**

## **INTRODUCTION**

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One of the most pressing challenges facing the long-term care system is the care of older persons with dementia (Health Canada, 1997; Ontario Ministry of Health, 1999; Ottawa-Carleton Regional District Health Council, 1995). Dementia is a term used to describe a collection of symptoms resulting from a failure of the brain (Patterson et al., 1999). It is diagnosed when cognitive impairments interfere with the social and occupational functioning of a person (American Psychiatric Association, 1994). In 1991, approximately 252,600 Canadians aged 65 and over suffered from dementia. Sixty-four percent of these people had a form of dementia called dementia, 19% had vascular dementia while other causes of dementia accounted for the remaining 17% (Canadian Study of Health and Aging [CSHA], 1994a). In Ottawa-Carleton, current estimates reveal that more than 6,400 older adults may be suffering from some form of dementia (Council on Aging of Ottawa-Carleton, 1999).

The majority of people with dementia have a family member who is primarily responsible for the provision of instrumental assistance and emotional support (CSHA, 1994b). As the cognitive ability of their relative decreases, these family members gradually assume the role of substitute decision-maker. Therefore, when circumstances dictate the need to seek alternative care arrangements, the search for appropriate options falls on their shoulders (Weisensee & Kjervik, 1989). In Ontario, long-term care options designed to meet the needs of people with dementia are either community-based (in-home and community support services) or facility-based (nursing homes, homes for the aged and retirement homes).

Researchers have found that many family members report a strong desire to keep their relative with dementia in the community for as long as possible, often risking their own health (CSHA, 1994b; Markiewicz, Reis & Gold, 1997; Teri, 1997), and turn to facility-based services only as a last resort (Rodgers, 1997). Consequently, the decision about whether their relative should receive care at home or be admitted to a care facility is often characterized by emotional turmoil and delayed decision making (Brody, 1971; McCarty, 1996; Tilse, 1998). These manifestations are possible indicators of decisional conflict. O'Connor (1997) defines decisional conflict as a state of uncertainty about a course of action experienced by individuals when choice among competing options involves risk, loss, regret or challenge to personal values. In 2000, a telephone survey of 635 Canadians conducted by O'Connor and her colleagues found higher decisional conflict in people deciding about long-term admission to a care facility.

Family members experiencing decisional conflict may benefit from receiving decision support (Deimling & Poulshock, 1985; Dellasega & Nolan, 1997; Grier, 1977; Powers, 1989; Rodgers, 1997; Smerglia & Deimling, 1997; Wackerbarth, 1999). In recent years, tools have been developed to assist nurses in providing decision support to those considering long-term care options for a person with dementia. These tools or decision aids are designed to provide information on the options, benefits and risks associated with this particular decision. Their goal is to structure and simplify the task of making a difficult decision. Although the effectiveness of these particular aids has not yet been formally established, decision aids developed for other decisions have been found to improve decision making by reducing decisional conflict, increasing knowledge, creating realistic expectations and improving the congruence between personal values and the choice made (O'Connor et al., 1997).

**This thesis unveils findings from a preliminary research study which developed and evaluated a decision aid for family members deciding whether their relative with dementia should receive care at home or be admitted to a care facility. The document is divided into five chapters. Chapter 1 presents results of previous research pertinent to the topic under study, the research objectives and the conceptual framework. A description of the development, content and format of the decision aid is found in Chapter 2. Chapter 3 explains how the decision aid was evaluated and Chapter 4 outlines the results of the evaluation. Finally, Chapter 5 discusses the significance of these results as well as their implications for nursing.**

## CHAPTER 1

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### **Review of Previous Research**

*This chapter summarizes findings from previous research on family members deciding whether or not their relative with dementia should be admitted to a care facility. It highlights what is already known about the decision support needs of family members and the interventions developed to address these needs. Following this review, the research hypotheses and the conceptual framework used to define the scope of the study are presented.*

A search of the studies published between 1966 to 2000 was performed using the following computerized databases: Medline, Cinahl, Health Star, Cochrane Database of Systematic Reviews, PsyInfo and SocioFile. The index terms used were decision making, choice behaviour, decision support, decision support techniques, Alzheimer Disease, dementia, family, caregiver, long-term care, home care, nursing home and institution. A hand search was also completed by examining reference lists of relevant documents. Finally, the World Wide Web was used to locate consumer information on long-term care services.

#### **Decision Support Needs**

A review of published studies suggests that several factors may have a bearing on the decision support needs of the targeted population. These factors are those associated with the individual characteristics of family members and their relative with dementia, the family members' appraisal of the available options as well as their perception of the wishes of important others, their readiness to change and their ability to implement the decision.

Researchers studying the relationship between the desire to seek admission to a care facility and the characteristics of family members and their relative with dementia found that family members were more likely to consider this option if they were white, female, employed and experiencing increased burden (Colerick & George, 1986; Morycz, 1985). Providing care to a parent as opposed to a spouse also increased the likelihood of ending care at home (Colerick & George, 1986; Markiewicz et al., 1997; Molloy, Bédard, Pedlar & Lever, 1999). The level of cognitive and functional impairment of the person with dementia was positively correlated with the desire to seek admission to a care facility (Cox, 1996; Gold, Reis, Markiewicz & Andres, 1995; Hinrichsen & Niederehe, 1994; Rockwood, Stolee & McDowell, 1996). Deterioration in the health status of the family member primarily responsible for caregiving was also attributed to the wish to end care at home (Nick & Douglas, 1991; Pratt, Wright & Schmall, 1987; Pruncho, Michaels & Potashnik, 1990).

The selection of a course of action appeared to be influenced by the family members' assessment of available long-term care options. Beliefs regarding the suitability or acceptability of a care facility as an alternative to in-home care was found to have a definite impact on the decision (Deimling & Poulshock, 1985; Kelley, Knox & Gekoski, 1998). Conflicting obligations, strong attachment bonds between family members and their relative with dementia and anticipated regrets about valued aspects of providing care at home were associated with vacillation and delayed decision making (Brody, 1966; Globerman, 1994; Lynott, 1983; Markiewicz et al., 1997; McCarty, 1996; Tilse, 1998). Feelings of uncertainty resulting from the family members' inability to predict the course of dementia and obtain adequate information about available options (Bowd & Loos, 1996; Fortinsky & Hathaway, 1990; McCabe, Sand,

Yeaworth & Nieveen, 1995; Wackerbarth, 1999) were linked to ineffective decision making (McGrew, 1998; Sims, Boland & O'Neil, 1992).

In an attempt to reduce uncertainty, many family members reportedly became more involved in the decision by seeking advice about long-term care options from health practitioners, peers and significant others. Physicians, social workers and nurses were found to be very influential when admission to a care facility was being considered (Cox, 1996; McAuley & Travis, 1997; York & Calsyn, 1977) but advice from acquaintances who had already made the decision was the source of social support most valued (Bell, 1996; Dellasega & Mastrian, 1995). In addition, most family members consulted with other family members before making a decision but only a few discussed the intended change with the dementia sufferer (Gold et al., 1995; Cox, 1996).

However, family members usually did not implement the intended change until a certain state of readiness was reached. This state of readiness appeared to vary as family members reached certain points along the change process (Noonan, Tennstedt & Rebelsky, 1999; Wackerbarth, 1999). With the exception of crisis which necessitates immediate action (Beckingham & Baumann, 1990), the decision as to whether or not to end care at home generally took place over an extended period of time (Lynott, 1983; Morycz, 1985) via a process that required early and periodic support interventions (Pruncho, Michaels & Potashnick, 1990). Some researchers suggested that failure to establish the family member's position along this change process could limit the effectiveness of support interventions or result in situations where people are inadvertently recruited into action (Cox, 1996; Degenholtz, Kane, Kane & Finch, 1999; McAuley & Travis, 1997).

Implementation of the selected option presented a challenge to family members who were reluctant to seek and accept assistance to execute the decision (Wilson, 1989). Low utilization of available services seemed to be a common occurrence among families responsible for a relative with dementia (McCabe et al., 1995). Unfortunately, many family members with a high need for and a willingness to use services reported problems related to availability, eligibility, affordability and quality (Collins, King & Kokinakis, 1994; Cox, 1996; Fortinsky & Hathaway, 1990; Zarit & Whitlatch, 1992).

#### Decision Support Interventions

Numerous research studies have examined the effectiveness of interventions designed to provide psycho-social support to family members of persons with dementia (Bourgeois, Schulz & Burgio, 1996; Knight, Lutzky & Macofsky-Urban, 1993; Thompson & Thompson, 1999) but only two studies among those reviewed specifically evaluated the efficacy of interventions supporting family members deciding whether their relative should receive care at home or be admitted to a care facility.

One of these two studies was a randomized controlled trial by Mittelman, Ferris, Schulman, Steinberg and Levin (1996) which set out to show that a program of counselling can delay institutionalization of persons with Alzheimer Disease. These researchers randomized 206 women who had a spouse with Alzheimer Disease living at home into an intervention group (n=103) or a control group (n=103). The intervention consisted of six individual and family counselling sessions plus weekly support group meetings. Ad-hoc counselling was also available upon request. The most frequent reasons for requesting a consultation were for emotional support (38%), advice about community-based services (21%), problems with patient

behaviours (18%) and decision support regarding admission to a care facility (8%). The median time from enrolment in the study to admission of the person with Alzheimer Disease was 329 days longer in the treatment group than in the control group ( $p=0.02$ ). This effect was greater in women whose spouse was suffering from mild-to-moderate dementia. These findings suggest that a program of counselling which includes decision support about long-term care options can substantially increase the time spouse caregivers care for their relative with dementia at home, particularly during the early to middle stages of dementia when admission to a care facility is generally least appropriate.

The second study evaluated the effectiveness of a computerized decision support intervention. Brennan, Moore and Smyth (1995) developed ComputerLink, a computer network designed to provide 24-hour in-home access to information and decision support. The decision support function was built on a multi-attribute utility model which employed questions to guide users through the analysis of a self-defined decision problem. A convenience sample of family members of persons with Alzheimer Disease was recruited. Participants were randomly assigned to either the computer group ( $n=47$ ) or the group receiving conventional support ( $n=51$ ). The majority of participants were educated, Caucasian female spouses. The median age was 64 years. During the one-year study period, the decision support function was accessed for a total of 91 times. In contrast, the chat line and e-mail were accessed 4,744 times. These findings suggest that family members do not perceive computer-based decision aids as a decision support instrument but more as a social support service (Gustafson et al., 1993).

Other decision aids for family members of persons with dementia are available (Alzheimer Society of Canada, 1998; Baycrest Centre for Geriatric Care, 1999; Canada Mortgage and Housing Corporation, 1999) but their effects have yet to be evaluated through research. These aids provide information on dementia and available long-term care options with little emphasis on value clarification and validation, two key factors in the decision under study (Dellasega & Mastrian, 1995; Sims, Boland & O'Neil, 1992) hence the necessity to develop a new decision aid. A systematic review of seventeen randomized trials of decision aids for persons facing medical treatment decisions, diagnostic tests decisions, preventative therapies decisions, clinical trial entry decisions as well as end-of-life decisions revealed that, when compared with the controls, decision aids improved people's knowledge about options, reduced their decisional conflict, and stimulated participants to take a more active role in decision making without increasing their anxiety (O'Connor, Rostom et al., 1999). Decision aids had a variable effect on the preferences of participants for certain options. They had no effect on satisfaction with the decision making process. When compared with simpler versions, more complex decision aids reduced decisional conflict and improved knowledge marginally but had no effect on satisfaction.

To conclude, researchers agree that some family members may require support when considering long-term care options for their relative with dementia but the effectiveness and suitability of decision support interventions currently available remain to be tested. However, caution must be taken when interpreting findings from the reviewed studies as few were based on large representative samples, incorporated multivariate analyses, included a control or comparison group or tested a clearly articulated theoretical framework.

## **Objectives and Hypotheses**

**This research study sought to accomplish the following objectives: (1) to evaluate the effect of a decision aid on the level of decisional conflict and knowledge of family members considering whether their relative with dementia should receive care at home or be admitted to a care facility; and (2) to describe family members' responses to the decision aid across the change process. The hypotheses were that family members using the decision aid would (1) experience decreased decisional conflict; and (2) be more knowledgeable about long-term care options available to persons with dementia.**

## **Conceptual Framework**

**The conceptual framework supporting this research study resulted from a combination of certain elements of the Ottawa Decision Support Framework (ODSF) and the Transtheoretical Model (TTM). The following paragraphs provide a description of each theoretical entity and define the conceptual underpinnings of the variables under investigation.**

**The Ottawa Decision Support Framework, which is based on expectancy value, decisional conflict and social support theories, was created for health decisions that are stimulated by a new circumstance, diagnosis, or developmental transition; generate uncertainty because of the value-sensitive nature of the benefits and risks; and require more effort during the deliberation phase than the implementation phase (O'Connor, Drake et al., 1999). As shown in Figure 1, the ODSF involves assessing the determinants of decision; providing decision support and evaluating the decision making process and its outcomes. These concepts pertain to all those involved in the decision, that is, the individual faced with the decision, significant others and the practitioner working with the decision maker.**

**Figure 1. The Ottawa Decision Support Framework**

Assess Determinants of Decision	Provide Decision Support	Evaluate
<p><b>Perception of Decision</b>            knowledge expectations values            decisional conflict stage of decision making</p> <p><b>Perception of Others</b>            perceptions of others' opinions &amp; practices support pressures roles in decision making</p> <p><b>Resources to Make Decision</b>            previous experience self-confidence motivation skill in decision making support (information, advice, emotional, instrumental, financial, professional help) from social networks and agencies</p> <p><b>Characteristics</b>  <u>client</u>: age, sex, marital status, education, occupation, culture, locale, medical diagnosis &amp; duration, health status  <u>practitioner</u>: age, sex, education, speciality, culture, practice locale, experience, counselling style</p>	<p><b>Provide access to information</b>            health situation options other's opinions and choices</p> <p><b>Re-align expectations of outcomes</b></p> <p><b>Clarify personal values for outcomes</b></p> <p><b>Provide guidance/coaching in :</b>            steps in decision making communicating with others handling pressure accessing support &amp; resources</p>	<p><b>Decision making</b>            improved knowledge realistic expectations &amp; norms clear values agreement between values &amp; choice implementation of decision satisfaction with decision making</p> <p><b>Outcomes of Decision</b>            persistence with choice improved quality of life reduced distress reduced regret informed use of resources</p>

The determinants of decision are listed in Table 1. These determinants are believed to shape, enable, and reinforce decisions. For example, choices people make not only depend on the personal characteristics of all involved but also vary according to their perceptions of the decision. Knowledge, choice predisposition for a certain option, the importance of expected gains and losses associated with choosing one option over another, as well as decisional conflict about which option is best ultimately influence decision making. Likewise, perceptions of what important others think is the appropriate choice, beliefs about what others in the same situation would do, pressure or support from others to select a particular option and people's perceived roles in decision making also have a definite impact on the decision. Finally, inadequate skills and resources can prevent some people from making and implementing the decision.

According to the ODSF, decision support interventions that specifically target determinants of decision which are modifiable can improve decision making. Tailored information about available options, value clarifying exercises and techniques to enhance decision making skills are interventions that can address sub-optimal determinants such as inadequate knowledge, unrealistic expectations, unclear values and inadequate resources and, by the same token, reduce decisional conflict. Decision support interventions are delivered using various aids such as decision boards, interactive videodiscs, computer programs, audiotapes, workbooks, pamphlets and group presentations and are usually supplemented by decision counselling (Janis, 1983; O'Connor, Drake et al., 1999; O'Connor, Rostom et al., 1999).

Table 1. Determinants of Decision According to the Ottawa Decision Support Framework

<b>Perception of the Decision</b>	
decisional conflict	-uncertainty about course of action to take
knowledge	-cognizance of the health problem or situation, options, and outcomes
expectations	-perceived likelihood or probability of outcomes of each option
values	-desirability or personal importance of outcomes of options
stage of decision	-phase of decision making : not thinking about options, actively contemplating options, close to selecting an option, takes steps toward implementation, acts.
<b>Perception of Important Others Regarding the Decision</b>	
opinions and practices of others	-perceptions of what others decide or what others think is the appropriate choice. For the client, important others may include their spouse, family, peers, and practitioner(s). For the practitioner, it may include the client, professional peers, and personal network.
pressure	-perception of persuasion, influence, coercion from important others to select one alternative
support	-informational, emotional, and tangible help from important others to bolster and sustain decision making
roles in decision making	-the way a participant is or wants to be involved in decision making with others; do they wish to make the choice themselves after considering other opinions, do they want to share decision making with someone else, do they want others to make the decision after considering their opinion
<b>Resources to Make the Decision</b>	
experience	-previous exposure to the situation, options, outcomes, decision making process
self-confidence	-belief in one's abilities in decision making, including shared decision making
motivation	-readiness and interest in decision making, including shared decision making
skills	-abilities in making and implementing a decision
assets from others	-instrumental and financial capabilities to implement choices -availability and access to information, advice, emotional support, instrumental help, financial assistance, and health & social services -social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors
<b>Characteristics of Those Involved in the Decision</b>	
client	-age, sex, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social)
practitioners	- age, sex, ethnicity, clinical education and specialty, practice locale, years of experience, counseling style

The ODSF defines an optimal decision as one that is informed, consistent with personal values, implemented and generates satisfaction with the decision making process (O'Connor, 1997). Therefore, decision support interventions are considered effective when people experience reduced decisional conflict; increased knowledge, realistic expectations, improved coherence with personal values, improved decision making skills and increased satisfaction. Persistence with choice, reduced distress and regret, appropriate use of resources and improved quality of life are other indicators of success.

Prochaska and DiClemente (1982), the creators of the Transtheoretical Model (TTM), believe that the success of any decision support intervention depends largely on people's readiness for change. While the ODSF stipulates that people's stage of decision can influence their perception of the decision, the TTM model goes a step further by suggesting that interventions be matched to people's current stage in a process unfolding over five stages and ten processes of change. Movement through this change process does not always occur linearly but rather cyclically as some people must make several attempts before the intended change is realized (Marcus, Rossi, Selby, Niaura & Abrams, 1992; Prochaska, DiClemente & Norcross, 1992; Prochaska & Velicer, 1997). The constructs of the model are outlined in Figure 2 and are further defined in the paragraphs below.

The five stages of change are: pre-contemplation, contemplation, preparation, action and maintenance. Pre-contemplation is the stage in which there is no intention to change in the foreseeable future. Contemplation is the stage in which people are aware that a change is needed within the next 6 months but they are not yet ready to take action. Preparation is a stage that combines intention with behaviour. People in this stage are intending to take action in the

Figure 2. The Transtheoretical Model

<b>Stages of Change</b>				
<b>Pre-contemplation</b>	<b>Contemplation</b>	<b>Preparation</b>	<b>Action</b>	<b>Maintenance</b>
Sees no need for change in the foreseeable future	Aware change needed within next 6 months	Intends to take action to bring about change within 1 month	Takes action to implement the change	Change in place for at least 6 months
<b>Processes of Change</b>				
<b>Consciousness raising</b> Seeks information about options				
<b>Dramatic Relief</b> Expresses strong feelings about change				
<b>Environmental Re-Evaluation</b> Considers effects on physical and social environment				
	<b>Self Re-Evaluation</b> Assesses personal values with respect to change			
	<b>Self-Liberation</b> Believes that change can be implemented and passes to action			
	<b>Social Liberation</b> Feels that implementation of the change is supported by society			
			<b>Contingency Management</b> Looks for ways to deal with problems that interfere with implementation of the change	
			<b>Stimulus Control</b> Controls factors that may trigger implementation problems	
			<b>Counter-Conditioning</b> Learns beneficial alternatives to cope with change	
			<b>Helping Relationships</b> Seeks support from others	
<b>Decisional Balance</b>				
Cons of changing > Pros			Pros of changing > Cons	

next month. They are getting ready to decide whether or not to implement the intended change. Action is the stage in which people modify their behavior, experiences, or environment in order to implement the change. Maintenance is the stage in which people work to consolidate the change.

The ten processes of change are strategies that people use to progress through the stages of changes. The relative importance of these processes depends on one's stage of change (DiClemente et al., 1991). For example, people in the pre-contemplation and contemplation stages have a tendency to seek information about the problem (consciousness raising), to express strong feelings about it (dramatic relief), and to consider how the problem affects their physical and social environment (environmental re-evaluation). The assessment of one's values with respect to the problem (self-re-evaluation) is usually performed at the contemplation stage while the belief that one can change (self-liberation) and awareness that society supports that change (social liberation) dominate the preparation stage. People in the action and maintenance stages attempt to modify the events that perpetuate the problem through the use of rewards and punishments (contingency management), to learn about beneficial alternatives that can substitute for the problem (counter-conditioning), to control the factors that trigger the problem (stimulus control), and to seek the support of others (helping relationship).

The change process also reflects people's relative weighing of the pros and cons of changing (decisional balance); considers the confidence people have about their ability to change under a specific set of circumstances (self-efficacy); and recognizes people's urges to move away from the intended change (temptation). Decisional balance is perhaps the most interesting of the three constructs because of its possible influence on people's progression

through the stages of change. In a study of the stages of change across twelve health behaviors, Prochaska and his colleagues (1994) found that the cons of changing were higher than the pros for people in pre-contemplation while the pros of changing were higher than the cons for people in action. These findings suggest that progression from pre-contemplation to action occurs as the pros of changing increase and the cons decrease.

It is important to note that the TTM is primarily used to explain decisions in which a particular choice is being promoted. In contrast, the ODSF is used in decisions where there is no right or wrong choice. The selection of an option depends on personal values and preferences. Hence, in the decision under study, the TTM was used to examine how family members moved to implement their preferred choice rather than promoting the adoption particular choice. In fact, combining the elements of the TTM and the ODSF may produce information needed to create a comprehensive blueprint for nursing interventions geared at supporting family members considering long-term care options for a relative with dementia. As noted in a joint study conducted by the Ottawa-Carleton Community Care Access Centre and the Champlain District Health Council (1999), actions must be taken to better address the support needs of people expressing the desire to seek admission to a care facility. Integration of elements from the ODSF and the TTM into practice may allow nurses to (a) plan tailored interventions which are matched to a set of predictable emotional and behavioral manifestations by family members and (b) develop and refine programs aimed at supporting this population.

## CHAPTER 2

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### **The Decision Aid**

*This chapter explains how the decision aid was developed and provides a detailed description of its content.*

#### **Development of the Decision Aid**

In 1998, Janet Allan created the first version of the current decision aid. The prototype was modeled after two decision aids based on the constructs of the Ottawa Decision Support Framework (Fiset, 1998; O'Connor et al., 1998). Shortly after, a development team composed of two geriatricians, a nursing researcher in decision sciences and this graduate nursing student was formed. Through an iterative review process, the decision aid was refined using research-based information and feedback from a practitioner review panel composed of experts in the field of geriatric nursing, social work, education and decision making. The revised version of the decision aid was then scrutinized by a family review panel comprising seven family members considering long-term care options for a relative with dementia. Content validity was established by asking these family members open-ended questions regarding the relevance and appropriateness of the information provided in the decision aid. Prevalent themes that emerged in response to these questions were incorporated into the decision aid. A copy of the decision aid is included in Appendix A.

#### **Content and Format**

The decision aid was formatted into a 25-page workbook containing brief and specific written instructions to guide its completion. The workbook addressed issues or topics identified

in research studies as having a significant impact on family members who were considering whether their relative with dementia should receive care at home or be admitted to a care facility. Information about the options available was based on the rules and regulations governing the Ontario long-term care system at the time of the study.

Throughout the workbook, several decision support methods were used to prepare family members for decision making. The first method involved the provision of information about dementia, the options available as well as the possible advantages and disadvantages of each option. The second method focused on validation and clarification of social norms by presenting three hypothetical situations that capture the variations in family members' decisions. The third method consisted of a value clarification exercise. Family members were asked to consider the advantages and disadvantages commonly associated with each option, to pick those they felt were most important, and to add others that may be relevant. Finally, through the use of a personal worksheet, coaching or guidance through the steps of decision making was provided. The workbook took approximately 30 to 45 minutes to complete.

## CHAPTER 3

**Research Methods**

*This chapter outlines the methodological decisions made to evaluate the decision aid. It provides a description of the research design, the population sampled and the procedures used to collect and analyze the measures selected for evaluation.*

**Research Design**

A one-group non-randomized before and after design was used to conduct the evaluation of the decision aid (Figure 3).

<b>Convenience Sample</b>	<b>Time 1</b>		<b>Time 2</b>
	Family members considering whether their relative with dementia should receive care at home or in a facility	<b>Baseline Questionnaire</b> -Characteristics -Decisional Conflict -Knowledge -Stages of Change -Choice Predisposition	<b>Intervention Decision Aid</b> -Problems Related to Dementia -Decisional Balance -Choice Predisposition

**Figure 3.** One-group non-randomized before and after design

### **Sample**

**The target population consisted of all family members of persons with dementia living in Ottawa-Carleton. To be eligible for the study, the persons with dementia had to live at home and family members had to have legal authority to make health care decisions on their behalf; be considering whether their relative should receive care at home or be admitted to a care facility and understand English. Family members who did not meet these eligibility criteria were excluded from the study.**

**A convenience sample of 27 family members was recruited with the assistance of staff from the Geriatric Assessment Unit of The Ottawa Hospital, the Ottawa-Carleton Community Care Access Centre, the Alzheimer Society of Ottawa-Carleton and the Psycho-geriatric Community Services of Ottawa-Carleton. Ethical approval for conducting this research study was obtained from all four recruiting agencies.**

### **Data Collection Procedures**

**Prospective participants were identified by staff of each of the recruiting agencies. Individuals who met the eligibility criteria and wished to participate in the study were asked to authorize staff to release their name and telephone number to the principal investigator. Appendix B shows the screening tool developed for that purpose. Within 72 hours of the initial screening, the principal investigator contacted the potential participant by telephone to provide general information about the study, confirm eligibility and make an appointment for an in-home visit to reiterate information about the nature of the participants' involvement. During the visit, family members were told that participation was strictly voluntary. It was made clear that refusal to participate or subsequent withdrawal from the study involved no penalty. Expected**

benefits and possible drawbacks associated with the intervention were discussed. Methods used to protect confidentiality and limit access to study data were reviewed with each participant. Individuals who still wished to participate were asked to sign a consent form (Appendix C). Those who needed more time to decide whether or not to participate were contacted at a later date. Only one follow-up call was made to each undecided individual. No monetary incentives were used to persuade individuals to participate in the study.

Upon obtaining consent, the principal investigator invited the participants to complete a self-administered baseline questionnaire (Appendix D). They were then provided with a copy of the decision aid and instructed to complete it at their earliest convenience. Once the task was completed, the decision aid was collected by the principal investigator. At that time, participants were asked to answer a self-administered post-questionnaire (Appendix E) which was retrieved immediately upon completion.

### **Evaluation Measures**

The baseline questionnaire evaluated the characteristics of the participants as well as the family members' level of decisional conflict, knowledge of the available options, position in relation to the stages of change and choice predisposition. Decisional conflict, knowledge and satisfaction were obtained using the post-questionnaire. Measures eliciting information about the characteristics of the person with dementia, decisional balance and choice predisposition were included in the decision aid.

Characteristics of family members and their relative with dementia. Characteristics of family members included age, gender, marital status, language, employment and education level.

Their health profile was established by asking them to rate their health from very good (1) to very poor (5). Questions about the person with dementia, kinship ties, living arrangement, length of the caregiving career, time spent on caregiving activities, problems encountered, the type of assistance required as well as the type of formal services used were asked to obtain information about the caregiving situation. The diagnosis of dementia was reported by staff of the recruiting agencies and confirmed by family members. Information about the family members' perceptions of the care recipients' cognitive and functional abilities was extracted from the decision aid. These measures were derived from studies that evaluated similar variables (CSHA, 1994b; Gold et al., 1995; Statistics Canada, 1997).

**Decisional conflict.** Decisional conflict was measured before and after the intervention using the Decisional Conflict Scale (O'Connor, 1995). The 12-item scale evaluated family members' perceived degree of uncertainty about the course of action to take and the extent to which inadequate knowledge, unclear values and inadequate support contributed to this uncertainty. Responses to the items were based on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree". The overall decisional conflict score ranged between 1 (low decisional conflict) to 5 (high decisional conflict). Evaluation of the psychometric properties of the scale with individuals who were considering decisions regarding immunization, cancer screening and treatment for schizophrenia revealed internal consistency coefficients ranging from 0.78 to 0.92 and test-retest reliability coefficients exceeding 0.80 (O'Connor, 1998).

**Knowledge.** The participants' knowledge was assessed using twelve questions pertaining to the information contained in the decision aid. Using a true/false/unsure response format, family members were asked to respond to twelve questions related to dementia and available

long-term care services. The same questions were asked in the post-questionnaire. Similar knowledge tests performed well in terms of internal consistency and sensitivity to change with decision support interventions (Fiset, 1998; O'Connor et al., 1998).

**Stages of change.** Family members' position along the stages of change was evaluated by asking them if they had submitted, on behalf of their relative with dementia, a request for admission to a care facility. The five-item algorithm was developed using guidelines established by DiClemente and colleagues (1991). The algorithm classified family members into the different stages of change: pre-contemplation, contemplation, preparation, action and maintenance. When comparing eight different algorithms used to stage health behavior, a study found that the five-item algorithm was the most valid and reliable method to ascertain a person's readiness for change (Reed, Velicer, Prochaska, Rossi & Marcus, 1997). To further evaluate the firmness of their intentions in regard to a possible admission to a care facility, family members were asked if they would accept, refuse or require more time to decide should a bed become available. A research study which used a similar question to assess family members' desire to admit a relative to a care facility found that significantly more persons (93%) whose caregivers at initial assessment had decided to end care at home were admitted to a care facility at follow-up two years later compared with 49% of persons whose caregivers had initially planned to continue care at home (Gold et al., 1995).

**Choice predisposition.** The participants' choice predisposition was determined by a 15-point scale with "care at home" to the far left and "admission to a care facility" to the far right with "unsure" situated in the middle. The scale also appeared at the end of the decision aid thus allowing assessment of the effect of the intervention on the intended decision. The test-retest

reliability coefficient of a similar question in a study evaluating a decision aid about hormone therapy was 0.91 (O'Connor, Tugwell & Wells, 1994).

**Decisional balance.** Decisional balance was assessed by comparing the number of advantages identified as relevant to family members for a particular option to the number of disadvantages for that same option. Each of the two options listed five advantages and five disadvantages which were identified in previous research as being important to persons making decisions about admission to a care facility (Bowers, 1988; Collins et al., 1994; Guberman, Maheu & Maillé, 1992; Gold et al., 1995; McCullough, Wilson, Teasdale, Kolpakchi & Skelly, 1993; Ross, Rosenthal & Dawson, 1997). Given the nature of the decision, the care at home option was considered a representation of the cons of changing while the care facility option represented the pros.

**Satisfaction.** The participants' satisfaction with the decision support intervention was evaluated by assessing the overall acceptability of the decision aid using three open-ended questions and six multiple choice questions. Satisfaction with the decision making process was measured using another set of six multiple choice questions. Similar questions have been used in previous studies evaluating decision support methods (Fiset, 1998; O'Connor et al., 1998).

#### Data Analysis

Descriptive statistics were used to analyze the characteristics of family members and their caregiving situation. Responses to questions measuring stages of change, choice predisposition and satisfaction were summarized using similar methods. Descriptive statistics were also used to examine responses across the stages of change. When available, excerpts from written comments submitted by the participants were selected to explain the meaning of

statistical analyses. To analyze differences in decisional conflict and knowledge before and after the intervention, a paired t-test was performed. This statistical procedure was chosen over the Wilcoxon signed-ranked test as recommended by Weiss (1995) because the distribution of the mean differences between the paired scores was normally distributed. An alpha level of 0.05 was used to indicate statistical significance.

### Sample Size

The sample size was selected based on paired t-tests for comparing the means of decisional conflict scores before and after using a decision aid (O'Connor, 1998). Effect sizes observed in these before/after studies ranged from 0.4 to 1.2. Based on these results, the effect size for this study was set at 0.8. Therefore, for a level of significance of 0.05, and power of 0.80, twenty-six family members were required to achieve a large effect (Cohen, 1977).

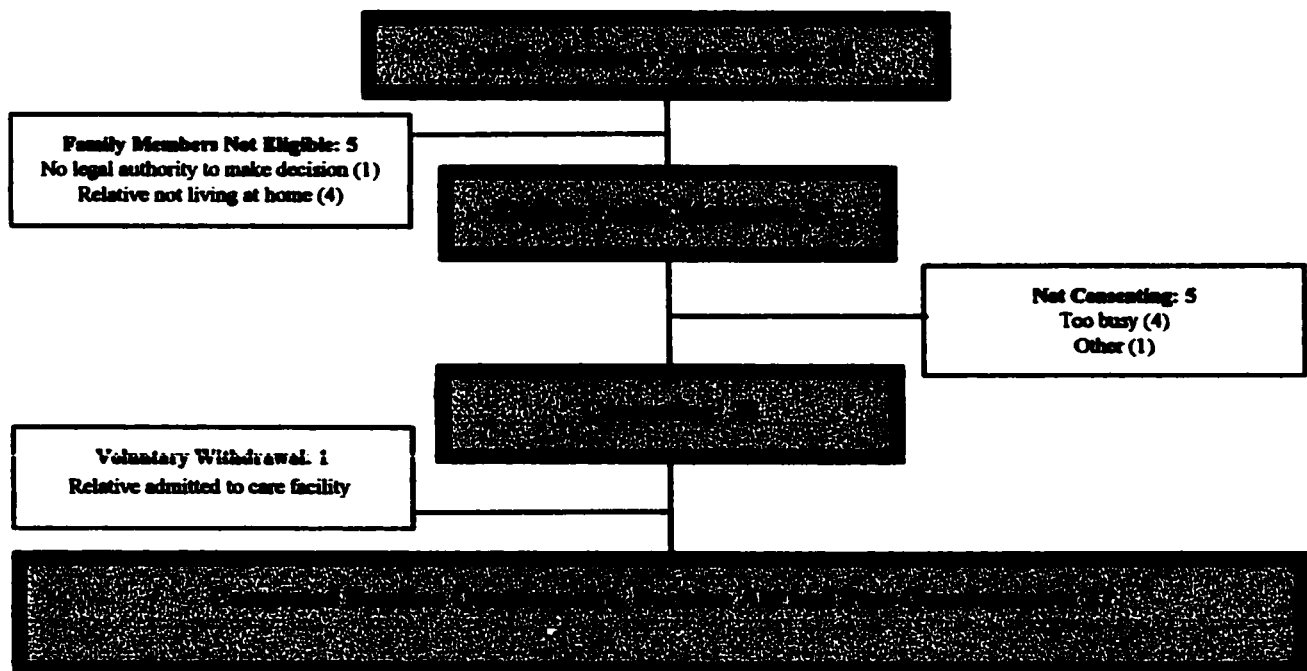
## CHAPTER 4

**Results**

*Chapter 4 summarizes the characteristics of the participants and their relative with dementia. It also provides a description of the results obtained when measuring decisional conflict, knowledge, stages of change, choice predisposition and satisfaction.*

**Recruitment of Participants**

The pilot study was conducted from November 1999 to July 2000. As shown in Figure 4, 38 family members were approached by staff from the recruiting agencies and 28 eligible family members accepted to participate in the study. One eligible family member withdrew from the study when her relative with dementia was admitted to a care facility. In total, 27 family members completed the baseline questionnaire, the decision aid and the post-questionnaire.



**Figure 4.** Flow of study participants

### **Characteristics of Participants and their Relative with Dementia**

**As indicated in Table 2, 15 family members were females and 12 were males. Their ages ranged from 35 to 85 years, with a mean age of 65 years. Over three-quarters were married and not employed. More than two-thirds of family members had received some education at the post-secondary level. The majority of participants were spouses of the person with dementia and reported being the primary caregiver for at least two to four years. Even though most family members spent over 20 hours a week on caregiving activities, the majority found time to be a member of a support group. When asked to rate their own health, 23 out of 27 family members reported that they were either in very good health or in pretty good health.**

**Table 3 shows that the typical person with dementia was female, living with the family member, and was reported to be experiencing problems with behaviors, activities of daily living, and emotions as well as cognition. Consequently, many persons with dementia required companionship, assistance with housework, transportation and finances. Sixteen care recipients required assistance with personal care tasks. Formal support services most often used by family members were homemaking services and day-away programs. Four persons with dementia used no formal support services.**

Table 2. Characteristics of Family Members (n=27)

Characteristic	Frequency
<b>Gender</b>	
Female	15
Male	12
<b>Age (years)</b>	
≤55	7
56-65	4
66-75	10
76-85	6
<b>Marital Status</b>	
Married or common law	24
Widowed, divorced or single	3
<b>Employment</b>	
Full-time or part-time	6
Not employed	21
<b>Education</b>	
Did not complete high school	2
High school graduate	6
Post-secondary	19
<b>Relationship to Person with Dementia</b>	
Wife	8
Husband	9
Daughter	7
Son	3
<b>Primary Caregiver</b>	
Yes	25
No	2
<b>Length of Caregiving Career</b>	
≤ 1 year	7
2 to 4 years	14
5 years or more	6
<b>Time Spent on Caregiving (weekly)</b>	
Less than 8 hours	4
9 to 40 hours	9
Over 40 hours	14
<b>Member of a Support Group</b>	
Yes	14
No	13
<b>Health Status</b>	
Very or pretty good	23
Not too good	2
Poor or very poor	2

Table 3. Characteristics of Persons with Dementia (n=27)

Characteristic	Frequency
<b>Gender</b>	
Female	18
Male	9
<b>Living Arrangement</b>	
Own home	6
Participant's home	21
<b>Problems with Thinking Process</b>	
1 to 3	8
4 to 6	19
<b>Problems with Emotions</b>	
No problems	3
1 to 3	10
4 to 6	14
<b>Problems with Activities of Daily Living</b>	
No problems	3
1 to 3	5
4 to 6	16
7 to 8	3
<b>Problems with Behaviors</b>	
No problems	4
1 to 3	21
4 to 6	2
<b>Type of Assistance Required</b>	
Personal care	16
Housework	24
Companionship	22
Finance	25
Transportation	25
Require assistance in all five areas	15
<b>Use of Formal Support Services (may use more than one service)</b>	
Assistance with personal care	6
Homemaking services	13
Home delivered meal	2
Day away program	12
Temporary admission to care facility	3
No services	4

### **Decisional Conflict**

**Family members' decisional conflict scores before and after using the decision aid are summarized in Table 4. As hypothesized, there was a statistically significant difference in total decisional conflict between scores obtained before and after the intervention ( $p=0.04$ ), with the post-intervention scores showing a reduction in decisional conflict from 2.5 to 2.1. When each subscale of the Decisional Conflict Scale (DCS) was examined, the 95% confidence interval of the differences between means had no overlap with zero for feeling uninformed and being unclear about values indicating statistical significance. However, there was overlap with zero for the subscales of feeling uncertain and unsupported. A closer look at the responses for each of the first 12 items of the decisional conflict scale revealed improvements in 10 of these items. In fact, the improvements from baseline in percentage of participants expressing no problems ranged from 11% to 26% for these 10 items.**

### **Knowledge**

**Results of the knowledge test are summarized in Table 5. As hypothesized, the mean knowledge test scores before the use of the decision aid improved significantly after the intervention ( $p=0.001$ ), with an increase equivalent to 24 percentage points. Improvements were noted in 11 of the 12 items. Items with the greatest percentage of improvement were those addressing the family members' understanding of the progression of vascular dementia or the incurability of Alzheimer Disease (45%), their awareness of the lack of provincial regulations for retirement homes (45%), their familiarity with the allowable maximum for homemaking services through the Community Care Access Centre (38%) and their cognizance of the rate reduction program available to Ontario residents with low income (37%).**

Table 4. Changes in Decisional Conflict (n=27)

	Before Decision Aid	After Decision Aid		
<b>Total DCS Score*</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>t statistic</b>	<b>p-value</b>
	2.5 (0.8)	2.1 (0.7)	-2.14	0.04
<b>Subscales Scores</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Difference</b>	<b>95% CI</b>
Uncertainty	2.9 (1.4)	2.8 (1.2)	0.1	(-0.61 to 0.57)
Uninformed	2.3 (1.0)	1.7 (0.5)	0.6	(-1.05 to -0.21)
Unclear values	2.3 (0.8)	1.9 (0.6)	0.4	(-0.66 to -0.11)
Unsupported	2.5 (1.0)	2.1 (0.9)	0.4	(-0.82 to 0.00)
<b>Expressing No Problems with Each DCS Item (score 2 or less**)</b>	<b>%</b>	<b>%</b>	<b>Difference</b>	
Easy choice	44%	44%	0%	
Sure what to do	56%	52%	- 4%	
Clear best choice	56%	67%	11%	
Know alternatives	70%	96%	26%	
Know advantages	70%	96%	26%	
Know disadvantages	70%	96%	26%	
Aware of:				
importance advantages	74%	93%	19%	
importance disadvantages	67%	93%	26%	
which more important	52%	70%	18%	
Feel no pressure	59%	82%	23%	
Have enough support	59%	78%	19%	
Have enough advice	48%	67%	19%	

\* Decisional conflict scale (DCS) scores are calculated by summing the scores from each item and dividing by the number of items. Scores range from 1 (low decisional conflict) to 5 (high decisional conflict).

\*\* To score 2 or less on one single item, a participant agrees or strongly agrees with an item.

SD Standard deviation

CI Confidence interval

Table 5. Changes in Knowledge Test Scores (n=27)

	Before Decision Aid	After Decision Aid		
<b>Total Knowledge Test Score*</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>t statistic</b>	<b>p-value</b>
	65% (15)	89% (10)	9.30	0.001
<b>Knowledge Test Score by Item,</b>	<b>% correct</b>	<b>% correct</b>	<b>Difference</b>	
Retirement Homes- admission and level of care required	96%	96%	0%	
Community Care Access Centre (CCAC)- access to services	96%	100%	4%	
Dementia and Alzheimer Disease- definitions	82%	93%	11%	
Adult Day Away Programs- description and associated costs	82%	96%	14%	
LTC Facilities- regulated by provincial government	74%	100%	26%	
Alzheimer Disease- most common, worsens over time	70%	93%	23%	
LTC Facilities- rate reduction for residents with low income	56%	93%	37%	
Short Stay Program- temporary admission to a LTC facility	48%	70%	22%	
Retirement Homes- not regulated by provincial government	48%	93%	45%	
LTC Facilities- resident charges for accommodation	44%	70%	26%	
Homemaking Services- maximum allowable hours/month from CCAC	44%	82%	38%	
Vascular Dementia and Alzheimer Disease - progression, no cure	37%	82%	45%	

\* Total knowledge scores are calculated by summing the number of correct responses and dividing this sum by the total number of items on the knowledge test. The quotient is then multiplied by 100 to obtain a percentage.

SD Standard deviation

### **Stages of Change**

Family members were classified at baseline into one of the five stages of change: pre-contemplation (n=11), contemplation (n=6), preparation (n=2), action (n=5) and maintenance (n=3). Given the small number of family members classified in the preparation, action and maintenance stages, data obtained from these participants were analyzed as aggregates and labeled post-contemplation. Five variables which were expected, on theoretical and empirical grounds, to be particularly salient in determining the nature of the differences across the stages of change were then selected for further analysis. The following paragraphs describe tentative patterns detected during the course of this analysis. The variables selected were decisional conflict, knowledge, hypothetical bed offer, decisional balance and satisfaction with the timing of the decision aid. The variables are listed in Table 6.

#### **Decisional Conflict**

At baseline, the total DCS mean score was highest in the pre-contemplation stage and lowest in the post-contemplation stages. When compared to scores obtained before the administration of the decision aid, improvements in decisional conflict were noted with the pre-contemplators and the contemplators as reflected in the lower scores at post-intervention. In contrast, the total DCS mean score of people in the post-contemplation stages increased by 0.18 after the use of the decision aid.

#### **Knowledge**

Before and after total knowledge test scores improved consistently across the stages of changes. Notably, precontemplators had the lowest baseline scores and made the greatest improvements in knowledge.

Table 6. Comparison of Five Variables Across the Stages of Change

Variable	Stage of Change at Baseline		
	Pre-contemplation (n=11)	Contemplation (n=6)	Post-Contemplation* (n=10)
	Mean (SD)	Mean (SD)	Mean (SD)
<b>Total DCS Score**</b>			
Before aid	2.70 (1.11)	2.54 (0.59)	2.21 (0.57)
After aid	1.94 (0.83)	2.01 (0.19)	2.39 (0.58)
<b>Total Knowledge Test Score***</b>			
Before aid	59% (10)	70% (13)	68% (20)
After aid	88% ( 8)	88% (17)	90% ( 8)
	Frequency (%)	Frequency (%)	Frequency (%)
<b>Hypothetical Bed Offer (before aid), no. of participants</b>			
Would refuse bed	10 (91%)	5 (83%)	5 (50%)
Would accept bed	0 ( 0%)	0 ( 0%)	3 (30%)
Not sure what would do	1 ( 9%)	1 (17%)	2 (20%)
<b>Decisional Balance (at intervention), no. of participants</b>			
# advantages > # disadvantages, care at home	8 (73%)	5 (83%)	3 (30%)
# advantages > # disadvantages, care facility	3 (27%)	1 (17%)	8 (80%)
<b>Satisfaction with Timing of Decision Aid (after aid), no. of participants</b>			
Most useful now	6 (55%)	5 (83%)	4 (40%)
Useful earlier	0 ( 0%)	1 (17%)	5 (50%)
Useful later	4 (36%)	0 ( 0%)	0 ( 0%)
Not sure	1 ( 9%)	0 ( 0%)	1 (10%)

\* Post-contemplation is a label used to identify the total number of family members in the preparation stage (n=2), the action stage (n=5) and the maintenance stage (n=3).

\*\* Decisional conflict scale (DCS) scores are calculated by summing the scores from each item and dividing by the number of items. Scores range from 1 (low decisional conflict) to 5 (high decisional conflict).

\*\*\* Total knowledge scores are calculated by summing the number of correct responses and dividing this sum by the total number of items on the knowledge test. The quotient is then multiplied by 100 to obtain a percentage.

SD Standard deviation

### **Hypothetical Bed Offer**

At baseline, no-one in the pre-contemplation stage and the contemplation stage indicated that they would accept an hypothetical bed offer. The only family members claiming they would accept a bed in a care facility if it was offered were in the post-contemplation stages. However, they were in the minority, as most of them (70%) reported that they would refuse a bed offer or require more time to decide.

### **Decisional Balance**

As hypothesized by Prochaska and colleagues (1994), the majority of family members in the pre-contemplation stage and the contemplation stage found that the number of advantages associated with providing care at home were greater than the number of disadvantages. In other words, the cons of changing the current caregiving situation exceeded the pros. The reverse appeared to be true for family members in the post-contemplation stages, with the number of advantages of an admission to a care facility higher than the number of disadvantages in 80% of the cases. The most frequently identified advantages to providing care at home were associated with being surrounded by personal belongings and pets (n=20), receiving care and services in the privacy of the home (n=19) and providing personalized care (n=18). The most frequently identified disadvantages of providing care at home were linked to the fact that many caregiving tasks remained the responsibility of the family even though services were being accessed (n=19), family members or friends were not always available to help (n=15) and the amount of services provided were not always sufficient to meet the assessed needs (n=10). For the care facility option, relief from most caregiving responsibilities (n=20), supervised environment to ensure safety and security (n=16) and services to meet most needs (n=13) were identified as the most

frequent advantages while less personalized care (n=18), lack of privacy (n=15) and less control over the quality of care provided were listed as the most frequent disadvantages.

### **Satisfaction With Timing of the Decision Aid**

The decision aid appeared to be more useful to family members in the contemplation stage. The fact that half of those in the post-contemplation stages reported that the decision aid would have been more useful earlier supports this observation.

### **Choice Predisposition**

At baseline, 20 family members were leaning towards providing care for their relative with dementia at home, three were unsure and four were leaning toward the care facility option. After the completion of the decision aid, only four changed their initial leaning and moved away from the care at home option: one of the three unsure participants moved toward the care facility option while 3 of the 20 leaning toward providing care at home moved to the unsure category (n=2) and the care facility option (n=1).

### **Satisfaction**

As shown in Table 7, over two-thirds of family members rated the amount of information included in the decision aid to be about right and found the information provided not at all upsetting. About one-quarter felt it was a little upsetting with two family members commenting that the decision aid forced them to “face the reality” and think about the decision they will have to make in the future. The majority found the 25-page workbook to be about the right length and indicated that the information provided was clear. Twenty-two family members felt that the decision aid presented the options in an impartial manner. Over three-quarters of the participants felt that the decision aid helped a great deal or a lot to think about the advantages

Table 7. Satisfaction of Family Members at Post-Intervention (n=27)

Item	Frequency
<b>SATISFACTION WITH DECISION AID</b>	
<b>Amount of Information</b>	
Much less than needed	1
Little less than needed	4
About right	19
Little more than needed	2
Lot more than needed	1
<b>Information Upsetting</b>	
Not at all upsetting	19
A little upsetting	7
Somewhat upsetting	1
<b>Length of Decision Aid</b>	
Little too long	2
About right length	24
Should have been a little longer	1
<b>Clarity of Information</b>	
Everything was clear	14
Most things were clear	12
Some things were clear	1
<b>Balance</b>	
Clearly slanted toward care at home	1
Slightly slanted toward care at home	2
Completely balanced	22
Slightly slanted toward care facility	2
<b>SATISFACTION WITH DECISION MAKING</b>	
Helped Think about Advantages/Disadvantages, a great deal or a lot	21
Helped Identify Questions to Ask, a great deal or a lot	18
Helped Prepare to Make a Better Decision a great deal or a lot	16
Helped Organize Own Thoughts, a great deal or a lot	15
Helped Look at Wishes of Relative a great deal or a lot	14
Helped Prepare to Communicate Opinion a great deal or a lot	14
Recommend Decision Aid to Others	
Definitely	24
Probably	3

and disadvantages of the options presented while just over two-thirds thought it helped them to identify which questions requiring answers. The most frequently documented question of family members was related to the admission day or, as one participant put it: “How do you convince a head strong person to accept that we must part and that she has to go to a home...how do I get her there?”

The decision aid was less successful at preparing family members to make a better decision, to organize their thoughts, to look at the wishes of their relative with dementia, and to communicate their opinion about the options. Nevertheless, almost ninety percent of family members would definitely recommend the decision aid to other family members considering long-term care options for a relative with dementia. In addition, several family members expressed the desire to complete the decision aid again in the near future to “monitor the progression of the situation” and “reaffirm (their) thinking regarding care” for the person with dementia.

## CHAPTER 5

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### Discussion

This preliminary study offers a number of insights into the feasibility and benefits of a decision support intervention for family members considering whether their relative with dementia should receive care at home or be admitted to a care facility.

As hypothesized, the findings suggest that family members experienced a significant decrease in decisional conflict following use of the decision aid. They felt significantly more informed about the decision and clearer about the values at stake. However, family members remained uncertain about what to do and improvements in feeling supported were not statistically significant. These results are compatible with studies involving persons deciding about hormone therapy, prenatal testing, chemotherapy for lung cancer and anticoagulation therapy (Drake, Engler-Todd, O'Connor, Surh & Hunter, 1999; Fiset, 1998; Man-Son-Hing et al., 1999; O'Connor et al., 1998). In these studies, decision aids were found to have a positive impact on decisional conflict and its modifiable factors but a more variable impact on uncertainty.

There are several possible reasons for the lack of shift in uncertainty. First, the decision aid was designed to only address the cognitive, affective and social factors that contribute to uncertainty (O'Connor, 1997). Other factors inherent to the choice dilemma may have been at play. One such factor is the lack of predictability associated with the course of dementia. Family members' assessment of the desirability of available options is often hindered by their inability to accurately predict how dementia will affect their relative (Wackerbarth, 1999). Although the decision aid was designed to provide family members with a set of procedures to

improve the quality of their assessment activities, the effectiveness of these procedures is limited by the absence of specific information about the anticipated needs of the person with dementia thus the importance of prompt recognition and assessment of dementia sufferers (Abraham & Neundorfer, 1990; Gauthier, 1999; Patterson et al., 1999). With a clear diagnosis, family members can make better predictions about the person's future care requirements and, by the same token, reduce uncertainty (Bell, 1996; Grier, 1977). Family members' uncertainty about the course of dementia lead a group of researchers to develop prediction algorithms to estimate the length of time from the onset of symptoms to admission to a care facility (Stern et al., 1997). This approach, although in its infancy, is an encouraging step toward providing information which will allow family members to make better decisions about the location of care.

Secondly, the decision aid was provided without follow-up counselling. As noted by O'Connor, Drake and their colleagues (1999), decision aids are developed to complement, not replace, counselling by health practitioners. The absence of counselling interventions to improve the effectiveness of the information search, to correct biases and to explore probable consequences may partly explain why family members remained uncertain. The lack of formal opportunities to obtain validation by significant others probably exacerbated the feelings of uncertainty (Bell, 1996; Dellasega & Mastrian, 1995).

Finally, the decision aid appeared to be less effective at reducing uncertainty with participants categorized in the post-contemplation stages as indicated by an increase in the total DCS mean score following the administration of the decision aid. It may be that the closer family members are to seeking admission to a care facility, the less receptive they become to information about other long-term care options (Neilsen, Henderson, Cox, Williams & Green,

1996; York & Calsyn, 1977). Exposure to alternative courses of action in the latter stages of the change process may force family members to re-evaluate a decision made on precarious grounds thus increasing uncertainty, and ultimately, decisional conflict. This phenomenon may explain why half of the post-contemplators felt the decision aid would have been more useful at an earlier time.

It was interesting to note that only post-contemplators reported that they would accept the hypothetical bed offer. However, the fact that 70% of family members in this combined category claimed they would refuse a bed offer or required more time to decide was even more interesting. These results suggest that some family members may be applying for admission to a care facility to simply profess their commitment to act. They may sound like they are ready to implement a decision but, in reality, are still evaluating the desirability of the available options and have no desire to proceed with the admission. According to Prochaska and Velicer (1997), this behaviour serves to enhance self-liberation and is typically exhibited by people in the preparation stage. Consequently, to accurately categorize family members in the post-contemplation stages, the intention behind the action must be known.

To progress from the preparation stage to the action stage, family members need detailed information about the preferred care option, practical strategies to accomplish the intended change and guidance through the steps of decision making. However, those with strong negative perceptions regarding the possible effect of a care facility environment on the person with dementia may still be tempted to refuse a bed offer (Deimling & Poulshock, 1985). As this study and others have shown, family members must believe that the pros of changing are greater than the cons before passing to action (Prochaska & Velicer, 1997; Velicer, Hughes, Fava &

Prochaska, 1995; Wackerbarth, 1999). Consequently, decision support interventions for family members in the preparation stage and the action stage should primarily focus on enhancing the advantages of admission to a care facility and identifying strategies to ward off the temptation to refuse the expected bed offer.

Regardless of their position in the change process, it was apparent that family members in this study had already accumulated a substantial amount of information about long-term care options prior to the decision support intervention. Nevertheless, an improvement of 24 percentage points was achieved following the completion of the decision aid, thereby supporting the second hypothesis. The fact that less than half of the family members were knowledgeable at baseline about the short stay program, the non-regulation of retirement homes, the accommodation charges in long-term care facilities and the allowable maximum hours for homemaking services was somewhat surprising. Sharp improvements in test scores for each of these items at post-intervention suggest that the decision aid was effective in disseminating information about these topics.

The decision aid had a minimal influence on the family members' choice predisposition as the majority continued to lean toward the option selected at baseline. This is likely due to the large number of family members who showed a strong bias for either one of the two options and the small number who were unsure. When movement did occur, the trend was toward the care facility option.

Although the majority of family members were generally satisfied with the decision aid, a number of them expressed reservations about its ability to improve their ability to decide. These results are not surprising given the inherent complexity of the issues facing family

members considering long-term care options for their relative with dementia. This finding emphasizes the importance of providing counselling interventions which focus on the process of decision making (Janis, 1983). Satisfaction with the decision aid may be linked to how well decision counselling interventions address this need.

#### Limitations

The major limitation of this study is the weakness of the sampling method used to select family members of persons with dementia. It is well known that convenience sampling is less likely to produce a representative sample of the targeted population. In fact, when the characteristics of the participants were compared with those of the community-based subset of family members from the Canadian Study of Health and Aging (1994b), notable differences were found. The mean age of our participants was 65 years with 52% of them aged 70 years or over. The mean age of the CSHA participants was 62 years with 36% aged 70 years or over. We also had fewer female participants (56% versus 75%) and more spousal caregivers (63% versus 37%). Daughters in our sample were slightly under represented (26% versus 29%) while sons were similar in numbers (11% versus 10%). Furthermore, 30% of our participants had applied for admission to a care facility at the time of the study while only 17% had done so in the CSHA. Given the non-representativeness of our sample, the results can only be generalized to family members of person with dementia included in the study.

It is also worthy to note that the time lapse between the administration of the baseline questionnaire and the post-questionnaire ranged from 3 to 29 days even though a telephone call was made 7 days after the initial visit. Therefore, it is quite possible that occurrences external to the study, such as exposure to a support group, communication with health care professionals

or unexpected changes in the caregiving situation, may have exerted an influence on the variables under study. Similarly, the passage of time may have altered the family members' initial views and feelings about certain variables. In addition, the effect of completing a baseline questionnaire on the family members' performance on the post-questionnaire presumably threatened the internal validity of the evaluation measures.

### **Implications for Nursing**

Clearly, family members deciding whether or not to admit their relative with dementia to a care facility have a great need for decision support. Nurses are well qualified to assess the extent of this need, and in conjunction with family members and their relative, identify and implement decision support interventions (Registered Nurses Association of Ontario, 1995). Frequent assessments must be conducted to develop stage-matched interventions that are relevant to the family's particular situation and responsive to the changing needs of those directly affected by the decision. Movement through the various stages of change hinges on the efficacy of these interventions (Prochaska & Velicer, 1997).

As family members move along the change process, nurses need to inform them about a variety of care options appropriate to the needs of their relative. Family members must be encouraged to involve the person with dementia when exploring available options. Dementia sufferers of diminished, uncertain or fluctuating decisional capacity may still be able to participate in decision making (Dubler, 1988). The person's own desires and wishes must be attuned to the family's ability and willingness to help. Depending on the circumstances, reconciliation between the care recipient's and family's preferences may be impossible to achieve. Hence, the importance of promoting anticipatory decision making as the lack of prior

discussion about admission to a care facility leaves family members without a basis for decision other than their impulse to care ( McGrew, 1998).

When exploring available care options with the family, nurses must remember that it is not sufficient to simply delineate the alternatives (York & Calsyn, 1977; Gonyea, 1987). Although the decision aid should enable nurses to adopt a more active approach to this information sharing process, education and guidance is required to help them develop the skills needed in assisting families to arrive at their own decisions and make the best possible choice with respect to whichever values and objectives they want to maximize (Janis, 1983). Decision support skills should be mastered by nurses working with dementia sufferers and their family. Practice guidelines, instructional booklets and other didactic tools are needed to help nurses acquire such skills.

Unfortunately, complex eligibility rules and policies, case management practices and scarce resources can limit nurses' ability to provide effective decision support interventions. For example, Degenholtz and colleagues (1999) found that specialization in intake tasks and higher workload were associated with a lower weight being placed on client preferences and a higher likelihood of recommending an admission to a care facility. Disparity between the expectations society has of family members of persons with dementia and the resources it is willing to provide to accommodate their preferences is also contributing to the problem (Nick & Douglas, 1991). Nurses need to advocate for policies that foster the creation of desirable care options, allow choice, and value the family unit as a whole.

### **Future Research**

**Future research need to identify and describe illness, caregiver and contextual factors that influence decision making about location of care. The complexities of this decision would probably be best understood if a controlled design with stratified random sampling was used (Molloy et al., 1999). Information gained from these homogeneous samples could then be used to design decision support interventions tailored to the specific needs of the family. However, nursing researchers evaluating these interventions will need to understand the factors that influence change and the processes by which change takes place to accurately assess their effectiveness (Gottlieb & Feeley, 1995). Longitudinal and repeated studies are needed to expand our knowledge in these areas.**

**Unfortunately, longitudinal controlled studies with stratified random sampling may not be feasible because family members of persons with dementia are difficult to recruit. As noted by Montgomery and Borgatta (1989), family members tend to be self-reliant and are reluctant to accept help until the limit of their tolerance has been reached. Already confronted with severe limitation on time and energy, family members are not always receptive to participating in a research study that may place greater demands on them or the person with dementia (Williams, 1993). In this study, recruiting strategies such as face-to-face contacts and referrals from initial sample members were found to increase family members' receptivity.**

## **CONCLUSION**

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**The decision about admitting a relative with dementia to a care facility is complex. It requires family members to select options in spite of uncertainty and multiple conflicting objectives. Without adequate support, family members are likely to make a decision that is uninformed, incongruent with the needs of their relative with dementia and in contradiction with their values. A decision aid, administered in conjunction with counselling, shows promise in helping nurses ensure that family members of persons with dementia make better decisions about location of care.**

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**Appendix A Making Choices: Care at Home or in a Care Facility**  
**A Decision Aid for Family Members of Persons with Dementia**

# Pilot Study

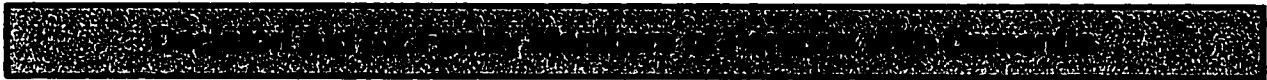
I.D. Code : \_\_\_\_\_

Date of Completion: \_\_\_\_\_



## **Making Choices:**

### **Care at Home or Admission to a Care Facility**



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**Allan, Comeau, Hing, Mitchell, O'Connor (February 2000)**




**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 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.**

- 
- 1** This Workbook is for You if...
  - 2** What is Dementia?
  - 3** How Does Dementia Affect Your Relative?
  - 5** How Does Dementia Affect You?
  - 7** How Do You Cope with the Effects of Dementia?
  - 8** Options for Persons with Dementia
  - 9** Option 1: Care at Home
  - 11** Option 2: Admission to a Care Facility
  - 13** Steps to Decision Making
  - 15** What Have Other People Like You Decided?
  - 21** Your Decision
  - 23** Suggested Readings and Other Resources
  - 24** References

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- **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 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 facility**
  
- **the steps to decision making**



**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**

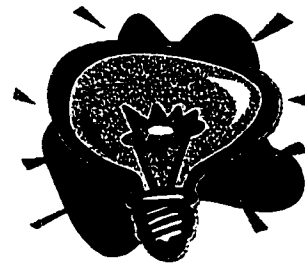
**This condition occurs when multiple pinpoint size strokes take place deep in the brain. Persons with vascular dementia may show a sudden decline in mental ability followed by a period of stability.**

**The vast majority of persons with dementia cannot be cured**

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



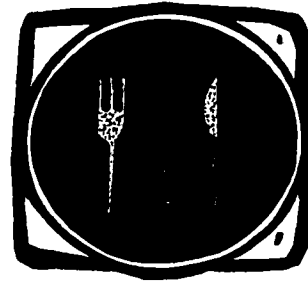
### Emotions

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



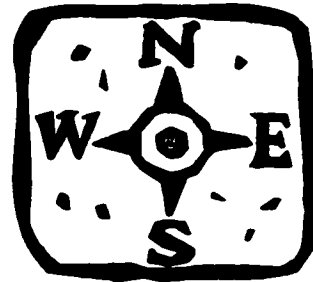
**Daily Activities**

- 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?

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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**

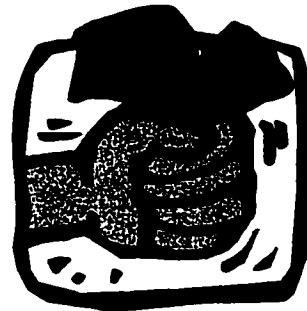
- Lack of sleep
- Increased fatigue
- Changes in appetite
- Worsening of existing health problems
- Other \_\_\_\_\_

**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?

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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



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:

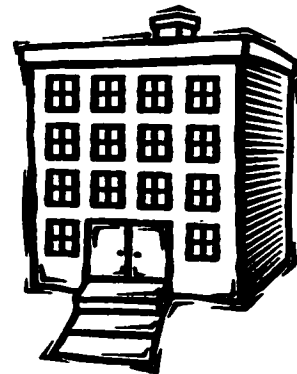
**Option 1**

Care at Home



**Option 2**

Admission to a Care Facility



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

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:

<b>Type of Service</b>	<b>Description</b>	<b>Service Limits</b>
<b>Nursing Services</b>	Assistance at home with health problems from qualified nursing staff	Up to 2 visits per day, based on assessed needs
<b>Personal Support Services/Homemaking</b>	Assistance at home with personal hygiene and routine activities of daily living	Up to 60 hours per month, based on assessed needs
<b>Therapy Services</b>	In-home physio, speech and occupational therapy to promote independence	Based on assessed needs
<b>Dietetic Services</b>	In-home nutritional counselling	Based on assessed needs
<b>Social Work Services</b>	In-home counselling and support for caregivers	Based on assessed needs
<b>Home Delivered Meal Services</b>	Provide hot noon meal at home	Delivered Monday to Friday
<b>Caregiver Respite Services</b>	Provide a few hours per week of in-home relief to primary caregiver	Usually provided within the Personal Support Homemaking limits
<b>Adult Day Away Programs</b>	Provide supervised group activities outside the home	Up to 2 days per week (overnight service also available)
<b>Short-Stay Programs</b>	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 \$4 per meal. Adult Day Away Programs charge between \$10 to \$30 per day including lunch. Short-Stay Programs charge approximately \$28 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



In this workbook, the words "care facility" include settings such as nursing homes, homes for the aged and retirement homes.

### **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**

Nursing homes and homes for the aged are also called "long term care facilities".

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 physio 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 \$1300 and \$1800 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 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



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 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 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?**

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 care facility?

### 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*

### 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 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

X														
Care at Home							Unsure							Admission to a Care Facility

## 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?



### 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

\_\_\_\_\_  
\_\_\_\_\_

### 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

- 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

\_\_\_\_\_  
\_\_\_\_\_

### 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!*

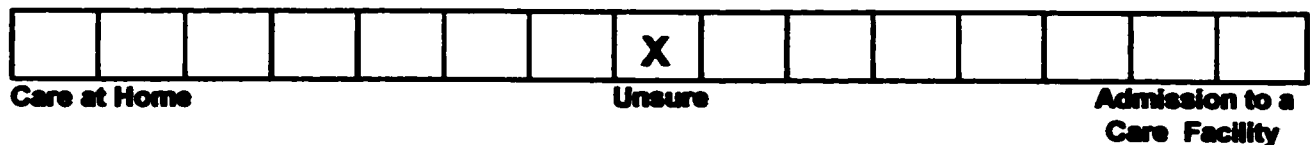
**Step 4** When does the decision have to be made?

- 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?



### 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
- \_\_\_\_\_
- \_\_\_\_\_

### 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

- 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

### 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
- \_\_\_\_\_
- \_\_\_\_\_



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 care facility?

**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

\_\_\_\_\_  
\_\_\_\_\_

**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**

- 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

\_\_\_\_\_  
\_\_\_\_\_

**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?

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**Step 3** How is this decision affecting me?

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**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

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**Step 6** My leaning

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Care at Home

Unsure

Admission to a  
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. & Chemin, 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)  
410-1223, Michael Street N.,  
Gloucester, ON  
K1J 7T2  
(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  
1525 Carling Avenue, Lower level  
Ottawa, Ontario  
K1Z 8R9  
(613) 722-1424**

**Office of the Public Guardian and  
Trustee, Ottawa Office  
244 Rideau Street, 3<sup>rd</sup> 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

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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.
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20. Health Care Consent Act, S.O.1996, C. C.2, s. 42.

**Appendix B Eligibility Screening Tool**

**Evaluation of a Decision Aid for Family Members Considering Long Term Care  
Options for Their Relative With Dementia**

## **Screening for Eligibility**

### **Purpose of the Study:**

The purpose of the study is to evaluate the effectiveness of a workbook designed to assist family members who are considering whether their relative with dementia should receive care at home or be admitted to a care facility. The principal investigator is Carole Comeau, a nurse currently studying at the University of Ottawa. Mrs. Comeau can be reached by pager at 598-9961 between 9 a.m. and 6 p.m., Monday to Friday.

### **Procedure:**

Family members will be asked to:

- ◆ complete the workbook (30-45 minutes); and
- ◆ to answer a questionnaire before and after the completion of the workbook (each questionnaire takes about 10 minutes to complete)

### **Screening Process:**

To be eligible, the family member must meet the following criteria:

<b>Eligibility Criteria</b>	<b>Eligible</b>	<b>Not Eligible</b>
The family member has legal authority to make personal care decisions on behalf of a relative with dementia in accordance with the Health Care Consent Act.	Yes ( )	No ( )
The person with dementia lives at home	Yes ( )	No ( )
The family member is considering whether the person with dementia should receive care at home or be admitted to a care facility	Yes ( )	No ( )
The family member understands English	Yes ( )	No ( )

**More questions on the back...**

**Evaluation of a Decision Aid for Family Members Considering Long Term Care  
Options for Their Relative With Dementia**

**Screening for Eligibility (cont'd)**

In your professional opinion, is the family member's current state of physical, mental and emotional health satisfactory to allow participation in this study?

Yes ( )

No ( )

**Determination of Eligibility Status:**

Is the family member deemed eligible?

Eligible ( )

Not Eligible ( )

**Willingness to Participate:**

If eligible, does the family member express the desire to participate in the study?

Yes ( ) Obtain written permission to release name and telephone number.

No ( ) State reason(s) for refusal: \_\_\_\_\_

**Permission to Release Name and Telephone Number:**

I, \_\_\_\_\_, was given permission by \_\_\_\_\_ at

Staff Member's Name

Client's Name

\_\_\_\_\_ to release his/her name and telephone number to Carole Comeau

Telephone Number

(principal investigator). Mrs. Comeau will provide my client with more information about

this research study within the next 72 hours.

Recruiting Agency: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix C Consent Form**

# **Information & Consent Form**

## **Title of the Research Study:**

**Evaluation of a Decision Aid for Family Members Considering Long Term Care Options for Their Relative With Dementia.**

## **Research Investigators:**

**Carole Comeau, RN, BScN, University of Ottawa**

**Dr A. O'Connor, RN, PhD, Professor, Faculty of Nursing, University of Ottawa**

**Dr. Malcolm Hing, MD, MSc, Geriatric Assessment Unit, The Ottawa Hospital (Civic Campus)**

**Dr. Susan Mitchell, MD, MPH, Geriatric Assessment Unit, The Ottawa Hospital (Civic Campus)**

## **Purpose:**

**The purpose of this research study is to evaluate the effectiveness of a workbook specifically designed to assist family members decide whether their relative with dementia should receive care at home or be admitted to a care facility.**

## **Procedure:**

**First, you will be asked to complete a questionnaire about you and the decision you are about to make. It will take approximately 10 minutes to complete this questionnaire. A researcher will then give you a copy of a workbook which contains information about dementia and the care options available to those affected by the disorder. The workbook can be brought home and usually takes 30 to 45 minutes to complete. Approximately a week later, a researcher will retrieve the workbook and ask you to complete another questionnaire. The second questionnaire is very much like the first one and should take about 10 minutes to complete.**

## **Risks and Benefits:**

**There are no anticipated risks associated with this research study. Some individuals may, however, find the decision they are about to make particularly difficult. If emotional support is needed during the course of the study, you will be referred to a health practitioner of your choice. Furthermore, upon completion of the second questionnaire, you will have an opportunity to discuss with a researcher your reaction to the research study.**

**There is no guarantee that you will benefit from participating in this study. Nevertheless, the workbook may provide you with valuable information and support in making your decision. If you wish to keep the workbook, a copy will be provided to you at no charge.**

**Confidentiality:**

Personal identifying information collected during this research study will be kept confidential. A code number will be used to identify your questionnaires and the workbook. Your name will not be used. The list of code numbers and the corresponding names will be kept separate from the rest of the data. Mrs. Comeau will be the only person to have access to this list. When not in use, the list will be locked in a filing cabinet.

Information obtained during the course of this study will be accessible only to the research team and if requested, to the Research Ethics Committee of \_\_\_\_\_. If the results of the study are published, your name will not be used in the published work.

**Voluntary Participation:**

Participation in this research study is voluntary. You are under no obligation to take part in the study, and you may withdraw from the study at any time. Whether or not you decide to participate will have no effect on the services you and your relative with dementia would normally receive.

**Consent:**

I have read this consent form and understand the information presented. I have had an opportunity to ask questions and adequate time to consider my options.

I agree to take part in this researcher study.

Name \_\_\_\_\_

Date \_\_\_\_\_

Witness \_\_\_\_\_

You will receive a copy of this consent form. If you have additional questions about this research study, you can contact the following persons:

Carole Comeau, RN, BScN, University of Ottawa  
Telephone number: 599-1942

Annette O'Connor, RN, PhD, Professor, Faculty of Nursing, University of Ottawa,  
Telephone number: 798-5555, ext. 3865

Chairperson, Research Ethics Committee of \_\_\_\_\_  
Telephone number: \_\_\_\_\_

**Appendix D** Baseline Questionnaire

**I.D. Code:** \_\_\_\_\_

**Date completed:** \_\_\_\_\_

**Evaluation of a Decision Aid for Family Members  
Considering Long Term Care Options for  
Their Relative With Dementia**

**Baseline Questionnaire**

**February 2000**

## Section A

Check (✓) the appropriate box(es) or fill in the blank line.

### 1. Gender:

Female

Male

### 2. Age:

\_\_\_\_\_years old

### 3. Marital Status:

married, common law

single

widowed

divorced/ separated

### 4. Employment Status:

full-time

part-time

not employed

### 5. Language most frequently spoken at home:

English

French

Italian

Chinese

German

Other\_\_\_\_\_

**6. Highest grade or level of education completed:**

- less than grade 9
- some high school
- high school diploma
- some college or university
- college diploma or university degree
- post graduate degree (Master or PhD)

**7. Relationship to Person with Dementia: You are his/her...**

- |   |   |                                     |
|---|---|-------------------------------------|
| <input type="checkbox"/> wife           | <input type="checkbox"/> husband        | <input type="checkbox"/> niece      |
| <input type="checkbox"/> daughter       | <input type="checkbox"/> son            | <input type="checkbox"/> nephew     |
| <input type="checkbox"/> grand-daughter | <input type="checkbox"/> grand-son      | <input type="checkbox"/> cousin     |
| <input type="checkbox"/> sister         | <input type="checkbox"/> brother        | <input type="checkbox"/> Other_____ |
| <input type="checkbox"/> sister-in-law  | <input type="checkbox"/> brother-in-law |                                     |

**8. Are you currently living in the same house as your relative with dementia?**

- Yes  No

**9. Are you the primary caregiver?**

- Yes  No

**10. How long have you been responsible for your relative with dementia?**

- less than 3 months       2 to 4 years       more than 10 years
- 3 to 6 months       5 to 7 years
- 7 months to 1 year       8 to 10 years

**11. What type of assistance does your relative with dementia require?**

- Personal care (feeding, toileting, dressing, bathing, medication)
- Housework, meal preparation, laundry, grocery, shopping
- Emotional support and companionship
- Management of finances and legal matters
- Transportation
- Other \_\_\_\_\_
- My relative does not require any assistance

**12. How many hours per week do you spend helping your relative with dementia?**

- less than 8 hours       21 to 40 hours
- 9 to 20 hours       over 40 hours

**13. What type of services are currently provided to your relative with dementia?**

homemaking services (cleaning, laundry, shopping, meal preparation)

home delivered meals (i.e. Meals-on-Wheels)

In-home assistance with personal care tasks

adult day away program

pre-planned temporary admission to a care facility

Other \_\_\_\_\_

My relative is not receiving any services

**14. How would you say your health is these days? Would you say your health is...**

Very good

Pretty good

Not too good

Poor

Very poor

## Section B

Below are listed some statements about dementia and the services available to those affected by this disorder. Please show whether you think they are true, false, or you are not sure by circling the appropriate word beside each statement.

### 1. About dementia:

Dementia is a term used to describe a group of symptoms	True	False	Unsure
---	------	-------	--------

One of the most common cause of dementia is Alzheimer Disease	True	False	Unsure
---	------	-------	--------

Persons with vascular dementia may show a sudden decline in mental ability followed by a period of stability.	True	False	Unsure
---	------	-------	--------

### 2. Persons with dementia who live at home:

can access an assortment of services through their local Community Care Access Centre (CCAC)	True	False	Unsure
--	------	-------	--------

could receive up to 60 hours per month of homemaking services	True	False	Unsure
---	------	-------	--------

can attend supervised group activities outside the home for \$10 to \$30 per day including lunch	True	False	Unsure
--	------	-------	--------

cannot be admitted to a nursing home or a home for the aged on a temporary basis	True	False	Unsure
--	------	-------	--------

**3. About care facilities:**

retirement homes are regulated by the provincial government	True	False	Unsure
nursing homes and homes for the aged are regulated by the provincial government	True	False	Unsure
retirement homes usually cannot admit persons who require a high level of care	True	False	Unsure
nursing homes and home for the aged charge well over \$2000 per month for accommodation	True	False	Unsure
nursing homes and homes for the aged offer a rate reduction to residents who cannot afford the cost of basic accommodation	True	False	Unsure

**Section C**

1. Have you submitted, on behalf of your relative with dementia, a request for admission in a care facility such as a nursing home, a home for the aged or a retirement home?
  - Yes, I have more than 6 months ago
  - Yes, I have less than 6 months ago
  - No, but I intend to in the next 30 days
  - No, but I intend to in the next 6 months
  - No, and I do not intend to in the next 6 months

2. If a bed was available right now in a care facility of your choice, you would:

- refuse the bed offered
- accept the bed offered
- require more time to decide

## Section D

If you had to decide right now whether your relative with dementia should receive care at home or be admitted to a care facility, show where you would be on the scale below:

- ◆ place a check (✓) far to the left if you choose care at home
- ◆ place a check (✓) far to the right if you choose admission to a care facility
- ◆ place a check (✓) in the middle if you are not sure

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**Care at Home**

**Unsure**

**Admission to a  
Care Facility**

## Section E

Now, thinking about the choice you just made, please look at the following comments made by family members deciding whether their relative with dementia should receive care at home or be admitted to a care facility.

Please show how strong you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree) which best shows how you feel about making this choice.

This decision is easy for me to make	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I'm sure what to do in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
It's clear what choice is best	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I'm aware of the options I have in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the advantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the disadvantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

I am clear about how <u>important</u> the advantages are in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about how <u>important</u> the disadvantages are in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about which is <u>more</u> important (the advantages or the disadvantages)	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I have enough advice about the options	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am making this choice without any pressure from others	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I have the right amount of support from others in making this choice	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

**Appendix E Post-Questionnaire**

**I.D. Code:**\_\_\_\_\_

**Date completed:**\_\_\_\_\_

**Evaluation of a Decision Aid for Family Members  
Considering Long Term Care Options for  
Their Relative With Dementia**

**Post-test Questionnaire**

**February 2000**

## Section A

Below are listed some statements about dementia and the services available to those affected by this disorder. Please show whether you think they are true, false, or you are not sure by circling the appropriate word beside each statement.

### 1. About dementia:

Dementia is a term used to describe a group of symptoms	True	False	Unsure
---	------	-------	--------

One of the most common cause of dementia is Alzheimer Disease	True	False	Unsure
---	------	-------	--------

Persons with vascular dementia may show a sudden decline in mental ability followed by a period of stability.	True	False	Unsure
---	------	-------	--------

### 2. Persons with dementia who live at home:

can access an assortment of services through their local Community Care Access Centre (CCAC)	True	False	Unsure
--	------	-------	--------

could receive up to 60 hours per month of homemaking services	True	False	Unsure
---	------	-------	--------

can attend supervised group activities outside the home for \$10 to \$30 per day including lunch	True	False	Unsure
--	------	-------	--------

cannot be admitted to a nursing home or a home for the aged on a temporary basis	True	False	Unsure
--	------	-------	--------

### 3. About care facilities:

<b>retirement homes are regulated by the provincial government</b>	<b>True</b>	<b>False</b>	<b>Unsure</b>
<b>nursing homes and homes for the aged are regulated by the provincial government</b>	<b>True</b>	<b>False</b>	<b>Unsure</b>
<b>retirement homes usually cannot admit persons who require a high level of care</b>	<b>True</b>	<b>False</b>	<b>Unsure</b>
<b>nursing homes and home for the aged charge well over \$2000 per month for accommodation</b>	<b>True</b>	<b>False</b>	<b>Unsure</b>
<b>nursing homes and homes for the aged offer a rate reduction to residents who cannot afford the cost of basic accommodation</b>	<b>True</b>	<b>False</b>	<b>Unsure</b>

## Section B

Now, thinking about the choice you made after using the workbook, please look at the following comments made by family members deciding whether their relative with dementia should receive care at home or be admitted to a care facility.

Please show how strong you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree) which best shows how you feel about making this choice.

This decision is easy for me to make	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I'm sure what to do in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
It's clear what choice is best	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I'm aware of the options I have in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the advantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the disadvantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

I am clear about how <u>important</u> the advantages are in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about how <u>important</u> the disadvantages are in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about which is <u>more</u> important (the advantages or the disadvantages)	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I have enough advice about the options	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I am making this choice without any pressure from others	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I have the right amount of support from others in making this choice	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I feel I have made an informed choice	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

<b>My decision shows what is important</b>	<b>1 Strongly Agree</b>	<b>2 Agree</b>	<b>3 Neither Agree Nor Disagree</b>	<b>4 Disagree</b>	<b>5 Strongly Disagree</b>
<b>I expect to stick with my decision</b>	<b>1 Strongly Agree</b>	<b>2 Agree</b>	<b>3 Neither Agree Nor Disagree</b>	<b>4 Disagree</b>	<b>5 Strongly Disagree</b>
<b>I am satisfied with my decision</b>	<b>1 Strongly Agree</b>	<b>2 Agree</b>	<b>3 Neither Agree Nor Disagree</b>	<b>4 Disagree</b>	<b>5 Strongly Disagree</b>

### **Section C**

**Check (✓) the appropriate box(es) or fill in the blank line.**

**1. What did you like the most about the workbook?**

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**2. What did you like the least about the workbook?**

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**3. How would you rate the amount of information in the workbook?**

- Much less than I needed
- Little less than I needed
- About the right amount of information
- A little more information than I needed
- A lot more information than I needed

**4. Did you find the information in the workbook upsetting?**

- Not at all upsetting
- A little upsetting
- Somewhat upsetting
- Very upsetting

Please comment: \_\_\_\_\_

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**5. How would you rate the length of the workbook?**

- Much too long
- Little too long
- About right
- Should have been a little longer
- Should have been a much longer

**6. How would you rate the clarity of the information in the workbook?**

- Everything was clear
- Most things were clear
- Some things were clear
- Many things were unclear

**7. How balanced and fair did you find the workbook?**

- Clearly slanted toward care at home
- Slightly slanted toward care at home
- Completely balanced
- Slightly slanted toward care in a facility
- Clearly slanted toward care in a facility

**8. How much did the workbook help you to organize your own thoughts about the decision?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**9. How much did the workbook help you to consider what you think about the advantages and disadvantages of each option?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**10. How much did the workbook help you to identify the questions you need to ask?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**11. How much did the workbook help you to look at the wishes of your relative in light of the present circumstances?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**12. How much did the workbook help prepare you to communicate your opinion about the options presented?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**13. How much did the workbook help prepare you to make a better decision?**

- A great deal
- A lot
- Somewhat helpful
- Very little
- Not at all

**14. Was it the right time to use this workbook?**

- The workbook would have been more useful if used earlier  
Explain: \_\_\_\_\_  
\_\_\_\_\_
- The workbook would have been more useful if used later  
Explain: \_\_\_\_\_  
\_\_\_\_\_
- The workbook is most useful to me now
- I am not sure when the best time to use the workbook  
would have been in my particular situation

**15. Would you recommend this workbook to other family members who are considering whether their relative with dementia should receive care at home or be admitted to a care facility?**

- Would definitely recommend it
- Would probably recommend it
- Would probably not recommend it
- Would definitely not recommend it

