EVALUATION OF BOOKLET
FOR CAREGIVERS OF
ALZHEIMER'S DISEASE

DESIGN AND EVALUATION OF A SELF-PACED LEARNING RESOURCE BOOKLET FOR CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER'S DISEASE

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ABSTRACT

Research in the last decade has focused on the impact of the caregiver role (Cantor, 1983), the nature of caregivers (Brody, 1981, 1983), and the stress and burden associated with caregiving (Zarit, Todd and Zarit, 1986). Health professionals working with caregivers have attempted to focus on interventions to reduce feelings of burden and to increase effective coping. Evaluation of educational interventions to reduce caregiver stress and burden has been a recent research focus. Unfortunately, research has shown that it is altruistic to believe that caregiver stress and burden can be alleviated by educational interventions.

Family caregivers are faced with the task of learning about the nature and complexity of dementia and the unusual behaviours which accompany Alzheimer's disease. A resource booklet, written to assist caregivers to learn about the disease, about management strategies and about their own feelings may be more effective than interventions to reduce stress.

The evaluation focused on whether the resource booklet would provide information which family caregivers would perceive to be relevant and useful. The evaluation was conducted using a convenience sample of ten caregivers. Two time intervals were used to collect information on caregivers' reactions to the resource booklet; one week following the initial reading of the booklet and 4-6 weeks post-reading. A written questionnaire at time one, and follow-up telephone interviews at time two, were used to measure caregivers' reactions to the booklet. Results indicated that the information in the booklet was useful in assisting caregivers to manage care, and that the caregivers found the booklet easy to read and the format acceptable.

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RATIONALE FOR THE PROJECT

1.1 Background

Alzheimer's disease is an increasingly prevalent dementia with no known cure. Scientists are only beginning to learn about the causes of this disease. Alzheimer's disease has frightening characteristics. These include insidious onset and progressive, irreversible loss of intellectual function (Cohen, 1990).

The nature of Alzheimer's disease renders the individual powerless and dependent. As memory and cognition fail, the person becomes unable to care for him/herself. Simple tasks such as personal hygiene, toileting and feeding become impossible for the individual to manage independently. As the disease progresses, family members must assume care and responsibility for the individual with dementia.

1.1.1 The Nature of Alzheimer's Disease

Alzheimer's disease affects approximately 300,000 Canadians and results in 10,000 deaths each year. Projections of dementia in the Canadian population have been forecast for the next forty years. In 1989, there was an eleven percent increase in the incidence of Alzheimer's disease over actual cases reported three years earlier in 1986. In 2001, it is projected that there will be a 44 percent increase over cases reported in 1986 and, that by the year 2031, the increase will rise to 163.8 percent (Hopkins, 1989). The increase in these population projections can be linked to an increasingly aged population. Although Alzheimer's disease can occur in middle-age, the incidence increases with advancing age and is particularly high in the over 65 year group. Gruetzner (1988) reported that two million Americans over the age of 65 years had Alzheimer's disease and that the incidence increased further with projections of 20 percent of the American population over the age of 80 years with dementia.

Alzheimer's disease is a condition of unknown origin in which there is a gradual loss of abilities in memory, thinking, reasoning, judgment, orientation and concentration. There is slow but progressive damage to the brain itself that is evident only upon autopsy. There is a slightly higher occurrence of the disease in women. There is no cure. The only treatment is to manage the symptoms and care for the person. Death is usually due to respiratory complications in the later stage.

The disease usually takes a course through three stages; early, middle and a later stage. There is no pre-set determination of the length of each stage. Some people progress fairly quickly; others may plateau for a while and then remain relatively stable. Alzheimer's disease can last from four to fourteen years, but the average duration is six to eight years (Kociol and Schiff, 1989).

At the early stage, the person with Alzheimer's disease experiences impairment in recent memory, concentration, reasoning and judgment. There are noticeable beginning changes in personality and behaviour. Often the individual can hide the symptoms and appears to family and friends to be healthy, although somewhat forgetful.

Memory loss, inability to concentrate, errors in judgment and problems in communication increase in the middle stage. The individual experiences disorientation, marked speech and language difficulties, and demonstrates increasingly difficult behaviours, such as agitation, wandering, anger or paranoia. Urinary incontinence may occur and generally, the individual has increased difficulty attending to personal hygiene, grooming and eating.

In the late stage, the dementia becomes profound and communication degenerates to a few phrases with no meaning. The person is totally dependent on someone else for all activities of daily living, such as feeding, toileting and dressing. The individual will be totally incontinent, immobile and will probably be bed-ridden. At this stage, frequently the individual's resistance to disease diminishes to the extent where he/she usually succumbs to a pneumonia or systemic infection or slips into heart failure. stop

In summary, Alzheimer's disease is an intellectual impairment that progresses gradually from forgetfulness to total disability (Mace and Rabins, 1981). Memory loss, often the first symptom, is followed by language difficulties, and then personality and behavioural changes (Lipkin and Faude, 1987). The loss of intellectual capacities impairs both the individual's social and occupational functioning.

As Gnaedinger (1989) pointed out, individuals with Alzheimer's disease are not the only victims; the people who care for them are also victims. The disease devastates marital and other relationships. The personality of the victim is changed and the caregiver is worn down by increasing responsibilities. The stresses felt by caregivers and their family members are overwhelming and cannot be understood by outsiders.

1.1.2 The Caregivers

* In the past decade, there has been an increasing

awareness of the major role that families play in caring for dependent family members. However, few people who take on the caregiving role fully understand its consequences. They often become caregivers at times of crises or during emergencies that require quick decision-making. They assume the caregiving role with the hope that they will help their loved one get better and that the situation will improve, only to discover that caregiving becomes all-consuming and progressive. Caregivers of the elderly, especially those diagnosed with Alzheimer's disease, face a future that promises little relief. They face only increasing dependence, declines, and ever more demanding physical care tasks (Brody, 1985). Combined with the unpredictability of tasks and uncertainty of prognosis, caregivers often must redefine what is a normal life and consider their future options.

Caregiving is not a time-limited episode, but spans the life course (Rossi, 1985). Many women experience a career of stages of caregiving from motherhood to middle-aged responsibilities for older relatives, extending into old-age responsibilities of caring for disabled or chronically ill husbands. Historically, the separation between men's and women's work has perpetuated the expectation that women's major role in life is to provide uncompensated care to dependents.

Demographic trends have radically altered the structure of the family such that there are ever increasing needs for informal caregivers in our society. For the first time in history, there is an increasing proportion of elderly in the population. Changes in the health care system, in public health measures, in improved nutrition and standards of living have increased life expectancy. The numbers and proportions of old and very old people have increased rapidly. These changes and shifts in the population will lead to increases in the need for filial care (Brody, 1990).

Smaller family size, that is lower fertility rates, have meant that older people have fewer adult children who can share the responsibilities of parent care. Families are more mobile. Fewer children live in the same city or centre as their parents. Most Canadian families now live on two incomes, with both spouses being employed. And with increasing divorce rates, many families are supported by single parents, usually the mother.

The increased number and proportion of elderly in the population and the rise in chronic diseases and disabilities that accompany increasing age places more families in the position of providing long-term care to aging parents. The results of increased longevity means that adult children are now providing more care, and more difficult care, to more parents and parents-in-law over longer periods of time than ever before (Brody, 1985).

Women generally assume the major responsibility for caregiving, and they appear to be less able than men to turn to their spouses for assistance (Stone, Cafferata and Sangl, 1987). Men, as caregivers, are less likely to be involved in direct "hands-on" care (Brody, 1985). Societal values hold that the provision of help to the disabled elderly is a family responsibility and, in particular, it is the role of the woman in the family (Brody, 1990). Caregivers are often under severe strain related to their multiple responsibilities. When women become caregivers, this role is added to their traditional family roles as wives, homemakers, mothers, employees, and grandmothers. These women are forced to respond to competing demands and to set priorities, as they struggle with multiple roles.

Women in the caregiving role have been characterized by Brody (1981) as "women in the middle". They are often in their middle years, yet they can be as young as twenty or as old as seventy. Often these women are the middle generation in three- or four-generation families. They are caught in the middle of conflicting values. The traditional caregiving role conflicts with the work role. They are torn between their responsibilities for their husbands and children, and the needs of their elderly ailing parents (Brody, 1990).

The experiences of women in the middle were documented in a study by Cantor (1983). She found that the children who provided care to the elderly were mainly married women with children, 60 percent worked and 45 percent provided financial assistance to their parents and/or parents-in-law. The married daughters continued to work and to meet their responsibilities to their families, jobs and elderly parents. They sacrificed free time and socializing with others to maintain their responsibilities.

Horowitz (1985) stated that two thirds of family caregivers are adult children and that caregiving daughters outnumber caregiving sons by three to one. If sons are designated as caregivers, they enlist the aid of their wives. Caregiving is primarily a female activity.

For many women, family caregiving is their preferred and chosen life's work. Filial love and sense of responsibility are strong. Families provide more than 80 percent of in-home care to elders (Hooyman, 1990). However, maintaining an older person with chronic care needs within the relative's home may place tremendous physical, financial and emotional pressures on family members.

Caregiving often affects women's emotional well-being, physical health, life-style and financial status (Brody, 1990). There are many restrictions and demands placed on caregivers. Freedom is lost. Time is very limited. There is isolation in being confined to the home. Problems in relationships with husband, family and friends often arise. Privacy and space are often sacrificed when the parent moves into the daughter's home for caregiving. Additional leisure time, social and recreational activities are curtailed as the caregiving role comes to dominate the woman's life.

Research has documented a variety of emotional consequences for caregivers. These include increased levels of depression, anxiety, helplessness, hopelessness, emotional exhaustion, low morale, feelings of isolation, guilt and anger (Cantor, 1983; George and Gwyther, 1986; Morcyz, 1985; Rabins, Mace and Lucas, 1982). Recent evidence from studies of caregivers suggested that increased absenteeism from employment was associated with caregiving. Data collected in the Informal Caregivers Study by Stone et al (1987) indicated that greater responsibility for the elderly may account for a significant portion of increased absenteeism and stress among women.

Caregivers generally lack social support. Caregiving tasks are performed in relative isolation from society and generally go unrecognized, except when there is abuse or neglect. Women are expected to know automatically how to be long-term caregivers and are blamed for failing to meet societal expectations (Hooyman, 1990). Although educational programs for caregivers have increased in the recent past, traditionally we have done little to prepare families to cope with these situations. There are few rewards for caregivers of individuals with Alzheimer's disease because the patient cannot reciprocate or show gratitude for the care received. Callahan (1988) has argued that even with adequate social supports, caregivers are often trying to meet impossible demands. He has suggested that caregivers have become victims. They are required to make heroic sacrifices in order to keep their relatives out of institutions. As Callahan so eloquently stated, "All things may be endurable if the demands are finite in depth and time. But a future that offers no exit at all, even if the burden on a daily basis is not utterly overwhelming, can be an obvious source of sadness and depression...No burden can be greater than trying to imagine how one can cope with a future that promises no relief" (p.325).

1.2 The Purpose of the Project

Caregiver burden is multi-dimensional affecting the family's physical, emotional, social and financial resources (George and Gwyther, 1986). Research in the last decade has focused on the impact of the burden on the caregiver (Cantor, 1983), the nature of caregivers (Brody, 1981, 1983), and the stress and burden associated with caregiving (Zarit, Todd and Zarit, 1986).

Professionals working with caregivers have attempted to focus on interventions to reduce feelings of burden and to increase effective coping (Pierce, Ader and Peter, 1989). For example, Kahan et al, (1985) investigated the efficacy of a group support program for caregivers. These researchers found that a relatively short but intensive support experience had positive effects in reducing some of the burden and depression associated with caring for a demented relative. However, as these researchers noted, the effects of these interventions were short-term. Caregivers continued to experience burden and depression due to the progressive nature of the disease and due to their continued roles as caregivers. It may be optimistic to believe that caregiver stress or burden can be alleviated by brief support interventions.

The need for education and information has clearly emerged from research on caregivers looking after demented relatives. Lichtenberg and Barth (1989) identified the behaviours of demented relatives which caregivers faced:

- the demand for more attention and care
- increasing dependence upon the caregiver
- declining memory and other cognitive dysfunctions
- catastrophic reactions
- night waking
- hiding things
- suspiciousness toward the caregiver
- physical violence
- communication problems
- incontinence
- increased irritability or apathy (p.32-33)

Caregivers must acquire understanding of the nature and complexity of dementia and the unusual behaviours which accompany the disease.* A curriculum designed to assist caregivers to learn about the disease, about management strategies and about their own feelings may be more useful than interventions to reduce stress or burden.

The purpose of this project was to design, implement and evaluate a learning resource booklet which could be used independently by caregivers to provide learning perceived by the caregiver to be relevant and applicable. The target population for the project was caregivers of individuals with Alzheimer's disease.

The curriculum consisted of an independent learning resource booklet for caregivers that was self-paced, easy to read and available at the learner's convenience. Content areas were identified from three sources of expertise: the caregivers, the research literature and the health professionals. Content areas were as follows:

- relevant information about the process of Alzheimer's disease,
- behaviour displayed by the Alzheimer's victim,
- safe management of these behaviours,
- ways the caregiver can look after him/herself,
- information about community resources.

The effectiveness of the resource was evaluated by measuring two primary outcomes:

i) caregivers' perceptions of the <u>usefulness</u> and <u>applicability</u> of the content;

ii) caregivers' perceptions of the <u>ease of use</u> of the resource and acceptability of the style of the resource booklet.

Evaluation took place at two time intervals; time one occurred within one week of reading the resource and time two within 4-6 weeks of reading the booklet. Evaluation of the outcome was based on responses to a written questionnaire at time one and a follow-up telephone interview at time two. In addition, the opinions of health professionals were sought regarding the benefits of the resource booklet.

1.3 Limitations of the Project

It was recognized that using written material is only one method of learning, and that individuals who could not read would not benefit from this type of design. Nevertheless, it is feasible that the resource booklet could be used by health professionals or other family members who could provide paced content to illiterate caregivers, or to interpret it for non-English speaking caregivers.

Many individuals are accustomed to learning from didactic presentations. It is recognized that a written booklet would have limited appeal to individuals who prefer a teacher-directed style.

In the best of all possible worlds, an ideal curriculum would include a variety of learning resources such as written, oral and visual. It was recognized that the costs of producing audio or videotapes was exorbitant for the purpose of this project. Moreover, some caregivers would have access to neither videotape players nor tape deck equipment, nor know how to operate these types of equipment. Hence, a written format was chosen.

Lastly, it was recognized that learning about Alzheimer's disease and how to provide care has limitations. Caregivers also need support groups with whom they can share their concerns. They need to learn problem solving techniques from others and feel that they are heard. Toseland and Rossiter (1989) reported on a review of studies examining support groups and found that although the participants indicated satisfaction with the groups, there were no links to reduction of stress, or improvement in skills. Thus one type of intervention alone does not provide adequate support to caregivers. Multiple interventions including support, education and respite care are needed.

CHAPTER 2

PRESENT STATE OF KNOWLEDGE

Three main topics were the focus of a review of the current state of knowledge. First was the nature of stress and burden on caregivers of individuals with Alzheimer's disease. Second were research studies investigating interventions to reduce caregiver stress and burden. And third were research studies on the effectiveness of specific educational strategies.

2.1 Caregiver Stress and Burden

In the past few years, researchers have studied the impact of caregiving and the nature of caregiver stress. Cantor (1983) reported on the results of an investigation of strain on caregivers. She found that emotional strain was pervasive among caregivers, but that the degree of strain was related to the closeness of the kinship bond. Caregivers were found to adjust their lives to provide care. This meant that the impact was greatest on their own personal lives. For example, it was found that caregivers often gave up their free time, their time to socialize with friends, and their vacations. Recommendations from this study included the need of caregivers for instruction on how to provide care, how to obtain support and how to access community services.

Brody's (1981, 1983 and 1986) findings about women as caregivers are frequently cited in literature reviews by other researchers. Brody (1981) coined the term "women in the middle". These women were caregivers to their children as well as to their parent(s). Typically, these women had jobs or careers, had reached middle age, and were looking forward to relinquishing a full-time commitment to family caregiving when they were called upon to look after a parent who was a victim of Alzheimer's disease.

The attitudes of women towards their role of caring for elderly parents has not changed over time (Brody, 1983). In spite of commitment to careers, to family or to attaining personal, or professional goals, women of all ages continue to feel responsible for looking after parents.

Caring for elderly, ill parents is a demanding task with major effects on the caregivers as documented in the literature. These effects include depression, chronic fatigue, anger, family conflict, loss of friends, no time for self, helplessness, resentment, interference in lifestyle and conflict from competing demands (Brody, 1986; Lund, Feinhauer and Miller, 1985; Horowitz, 1985). If assistance can be given to caregivers, it needs to focus on providing relief from caregiving to enable some patterns of normal living to be resumed. Respite programs such as the Victorian Order of Nurses' Caregiver Support Program offer caregivers time away from the dependent person by providing a paid helper in the home. Other programs such as St. Peter's Hospital Day Program and the Victorian Order of Nurses' Adult Day Centre, provide respite hours to allow caregivers to carry on usual daily activities such as shopping, working or socializing. Respite programs are effective in reducing some caregiver stress and strain (Mohide et al, 1990).

"Women in the middle" are one group of caregivers. Another group is elderly spouses, both men and women. Zarit, Todd and Zarit (1986) reported on a longitudinal study examining the concept of burden. These researchers defined burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (p.261). Using the Burden Interview tool designed by one of the researchers, this team found that women generally reported more subjective burden than men. Interestingly, the researchers found that caregivers' tolerance to burden increased as the care recipient's behaviour worsened and as the disease (Alzheimer's) progressed. Moreover, it was found that caregivers reacted differently to the stress of caregiving and not all caregivers found the care recipients' behaviours to be difficult or troublesome. Hence, this study confirmed other researchers' (Lazarus and Folkman, 1984) findings that the impact of harmful events depends upon each individual's perception of harm and his/her ability to cope with the problem.

Historically, health professionals have focused on the behaviours of the ill person without recognizing how caregivers' well being suffers. The burn-out syndrome has been associated in the literature primarily as an experience of professionals. However, Ekberg, Griffith and Foxall (1986) found symptoms of the burn-out syndrome in a small group of caregivers.

The psychological and emotional impact on caregivers has been confirmed in research studies. Eagles et al (1987) found significant increase in levels of stress experienced by a group of caregivers in Scotland. Gallagher et al (1989), found a high incidence of depression among family caregivers, with women being more depressed than men.

A national profile of caregivers in the United States was undertaken by Stone, Cafferata and Sangl (1987). This study found that caregivers were predominantly female, many were over the age of 65 years and few used formal services to assist in caring for a demented relative.

In summary, there has been considerable research conducted on the impact of caregiving on family members of persons with Alzheimer's disease. Caregivers range from being highly stressed and burdened in their role to being able to cope effectively with daily activities. Most caregivers are women, usually daughters or daughters-in-law and their lives are significantly disrupted. These caregivers are committed to looking after an ailing, elderly parent, in spite of the impact on their personal lives. Lastly, as described by Stone et al (1987) and confirmed by other researchers, caregivers attempt to meet the care recipients' needs without outside help.

2.2 Research Studies on Interventions

Recognizing the impact of caregiving, some researchers have attempted to implement and evaluate interventions to reduce stress and burden for the caregiver. Crossman, London and Barry (1981) attempted to implement a model of supportive services for elderly wives caring for a disabled spouse. The model consisted of respite care, home care, support groups for the women and a community workshop. Unfortunately, these researchers failed to establish any correlation between the implementation of these services and the ability of the women to meet the caregiving demands.

Similarly, Aronson, Levin and Lipkowitz (1984) designed support groups for caregivers in which education was a component. The program did not include well designed evaluation strategies and although the authors reported positive outcomes, the results cannot be confirmed. In this project, the caregivers had to travel some distance to reach the group, many by public transit. Many caregivers were eliminated from the sample because they were unable to leave the care recipient. This educational design has limited generalizability because it is resource-intensive, requiring skilled staff able to devote time and energy on a weekly basis.

Zarit, Anthony and Boutselis (1987) conducted a randomized controlled trial to evaluate two types of interventions: a support group and individual and family counselling. Education was a component in both experimental arms of the design. The goal was to provide the caregivers with training in managing behaviours. The researchers hypothesized that relief of stress would be an outcome. Although subjects in the treatment groups made significant gains, and these gains were maintained at a one year follow-up, the treatment groups did not differ significantly from the control group. This study experienced many problems. There was a high rate of attrition; behaviour management was not a focus of interest for the caregivers; and the study period was only seven weeks long, too short a time period to have a significant impact on stress reduction. Moreover, the researchers found that many caregivers did not believe that management of their stress was an appropriate or potentially beneficial intervention.

Haley, Brown and Levine (1987) implemented a randomized controlled trial to evaluate the effectiveness of group interventions for caregivers of elderly dementia patients. The design can be criticized from two perspectives. First, participants were recruited from local Alzheimer's Disease Society lists thus confining the potential study population to a selected group. Secondly, the primary author, Haley, acted as one of the group leaders which created a bias in the design.

The educational intervention consisted of didactic presentations and the distribution of a book and several brochures about Alzheimer's disease. Poor attendance reduced the likelihood of significant outcomes. In this investigation caregivers had to travel to attend the sessions. Some reported being unable to find a sitter, and some were themselves too ill to attend. These researchers used various standardized evaluation tools such as the Beck Depression Inventory, the Life Satisfaction Index - Z and the Health and Daily Living Form. The results did not show significant differences between the treatment and intervention groups. Once again, the researchers attempted to reduce caregiver stress in a relatively short period of time. Caregivers, on the other hand, reported valuing outcomes such as increased knowledge about the disease and coping skills that would allow them to face the progression of the dementia. Moreover, the subjects were reported to be as much or more concerned about improving their effectiveness as caregivers as they were with reducing stress.

British researchers (Sutcliffe and Larner 1988) compared two methods of counselling caregivers. Subjects receiving counselling and support reported a decrease in stress compared to those receiving information alone. Information was given in the form of booklets and brochures and was found to be effective in increasing knowledge of dementia.

Montgomery and Borgatta (1989) conducted a randomized controlled trial involving five treatment groups. The duration of the trial was one year, a significantly longer trial period than used in studies reported previously. This study had a large sample size (541 families). The curriculum addressed a variety of topics including changing family roles, communication skills, aging, community resources and legal concerns. Standardized measurement tools were used to determine the extent of subjective and objective burden. There was a high attrition rate from the study, primarily due to participant's inability to attend sessions. One major finding of this study was that caregivers, who are already challenged by limitations on time and energy, were not receptive to services that placed greater demands on them.

Zarit and Toseland (1989) and Haley (1989) made many relevant points for researchers attempting to demonstrate that interventions can be effective in reducing caregiver stress. First, they cautioned that time-limited psycho-educational interventions cannot be measured well by global ratings of well-being, mood, stress and burden. Researchers need to focus on specific goals and utilize measurements designed for those outcomes. Attempts to measure reduction in stress levels may be misleading since caregiver stress fluctuates with changing circumstances. For this reason in addition, before-and-after designs may not be an effective means of measuring changes. Finally, interventions requiring caregivers to attend sessions away from home may produce results that are of limited statistical significance due to low attendance and attrition. Problems with transportation and with finding someone to stay with the care recipient are common among caregivers.

2.3 Research on Educational Strategies

Independent learning resources such as books, pamphlets and tapes, have been found to be an effective way to provide opportunities for learning. Hiemstra (1976) found that interest in self-directed learning activities existed in a population of older adults. Christopherson and Pfeiffer (1980) compared anxiety scores of subjects reading informational booklets before their operations with subjects who did not read these booklets. They found that anxiety scores were significantly lower for the experimental group and that there was an increase in knowledge scores. Rice and Johnson (1984) evaluated the effects of pre-admission self-instructional booklets and found the booklets effective in achieving mastery of exercise behaviours.

Wong and Wong (1985) evaluated the effectiveness of an individualized learning activity package to teach hip replacement patients to perform postoperative exercises. The 98 subjects were assigned randomly to an experimental or control group. Dependent variables included compliance, satisfaction and complications. Experimental subjects showed a significantly higher degree of compliance and were more satisfied than those in the control group.

Regner, Hermann and Ried (1987) evaluated the effectiveness of a printed leaflet in teaching patients about digoxin side-effects. Effectiveness of the information strategy was measured by the ability of patients to use the information as a basis for recognizing side effects and deciding what to do. The leaflet was found to be an effective means of enabling patients to make appropriate decisions. Effectiveness of the leaflet was enhanced by verbal instructions.

Laine et al (1989) evaluated an educational booklet for parents of children receiving total parenteral nutrition. The results of the study showed that the use of the booklet reduced anxiety in the parents and increased their satisfaction with patient care.

Studies such as those cited above confirm that independent learning resources are an effective means of providing opportunities for learning. Using a self-paced format for learning is in keeping with principles of adult education. Adults are more inclined to read material that is immediately useful (Knowles, 1984).

With respect to the concepts of teaching and learning, Gessner (1989) made an interesting observation.

She stated that "teaching does not guarantee learning, and learning can occur without a teacher" (p.591). Self-paced learning resources are designed for learning to occur without a teacher.

Increasingly patient educators are advocating for change in the way that education is presented. Roter (1987) emphasized active partnership and participation with the patient, finding out what the patient wants to know and presenting information with his/her active participation. Strategies which are learner-centred and learner-active are the most efficacious methods of transferring knowledge. When learners are allowed to choose when and what to learn or whether to learn, they are emancipated and freed to make their own decisions. This approach presents a more humanistic view of learning. Too often health professionals demand patient compliance. They try to change the patient's behaviour so that it is in keeping with medical advice (Hussey and Gilliland, 1989). In this instance, learning is imposed not negotiated with the learner.

Control of an individual's learning should rest with the learner. Research conducted by Kim (1986) examined learning performances under three conditions; fast-paced, slow-paced and self-paced. She found that learning performance under the self-paced condition was superior to the two experimenter-paced conditions, and that a self-paced response condition was advantageous for the elderly.

Studies such as those cited above confirm that independent learning resources are an effective means of providing opportunities for learning. Adult learners, including the elderly, have been found to benefit from this learning method.

CHAPTER 3

DESIGN OF THE PROJECT

3.1 Development of the Resource Booklet

The goal of the project was to develop a learning resource booklet for caregivers that was self-paced, easy to read and readily available to caregivers of persons with Alzheimer's disease. Content areas were identified based on three sources of expertise: the medical and nursing literature, caregivers with recent experience in looking after a relative with Alzheimer's disease and the experiences of health professionals in the field.

Literature sources indicated several content areas of use to caregivers. Hayter (1982) found in her work with caregivers that the four most frequently requested content areas were as follows; first, cause, treatment and prognosis of the disease; second, responsibilities of family members; third, negative feelings towards the patient; and fourth, contact with others interested in Alzheimer's disease. Gwyther and Matteson (1983) and Henri (1980) highlighted the need for education on how to manage the behaviour of individuals with Alzheimer's disease.

Greene and Monahan (1989) noted problems of caregivers who lacked information on practical, how-to techniques of caregiving, community resource utilization and stress management. Noelker and Bass (1989) supported educating family caregivers on using formal services, that is, community resources.

Many books written for caregivers such as *The 36-Hour Day* by Mace and Rabins (1981); *Alzheimer: A Canadian Family Resource Guide* by Kociol and Schiff (1989) and *Alzheimer's: A Caregiver's Guide and Sourcebook* by Gruetzner (1988) were reviewed for content. Other books written for health professionals were also reviewed and found to be too medically-oriented for the purpose of the resource booklet.

The literature provided general themes for content areas. The usefulness and relevance of the content were then explored with and confirmed by three caregivers who volunteered to assist with a review of the draft of the booklet. These caregivers consented to be interviewed so that the writer could identify their perceptions of the needed content areas. All three caregivers had looked after an individual with Alzheimer's for some time. Appendix A outlines the interview questions and the responses given. The interviews were held at the caregivers' convenience and lasted no more than one hour. Notes were recorded with the caregivers' permission.

Lastly, once the content areas were outlined, two health professionals were asked to give their opinions of the outline. Both these individuals have worked with caregivers and have provided educational sessions to caregivers or support workers.

The writer took care to use a writing style that could be read by people with varying levels of reading comprehension. Health professionals tend to use complex writing styles, and to use medical terminology and jargon (Hilts and Krilyk, 1989). The resource was written using words with few syllables and an uncomplicated style so that it had the potential to be read by individuals with low literacy skills (Doak, Doak and Root, 1985).

Illustrations were used with moderate frequency to provide visual cues to the reader and also to emphasize key concepts. The text was varied by using a variety of type styles to retain the reader's interest. Finally, at the end of each section, a "Time for Reflection" was introduced. The purpose of these pages was to provide a pause in the learning sequence by asking the reader to consider how he/she might use the new information and the insights provided. In self-paced instructional resources designed for students, often there are tests to encourage the student to review the knowledge acquired. It was felt that using a similar test model would not be appropriate. A test might be perceived to be threatening to an already stressed caregiver. A selected bibliography was added at the end of the booklet to provide additional resources for the caregiver.

The learning resource booklet was examined by the three caregivers who were interviewed regarding their responses to content areas. They suggested a few improvements such as clarification of some words and rephrasing of some sentences. Overall, their reaction to the resource was positive. Comments made by the caregivers during the evaluation sessions and their background sketches are summarized in Appendix B. Changes to the resource were made according to the responses of the caregivers.

3.2 Design of the Evaluation Component

The design of the self-paced independent learning resource booklet for caregivers was evaluated on the basis of two measures of outcome. These were; first, the caregivers' perceptions of the usefulness and applicability of the content, and second, caregivers' perceptions of the ease of use of the resource and acceptability of the style of the resource booklet. These outcomes were selected because the research studies had shown that outcomes such as reduction of stress and burden were seen as desirable but unachievable as a result of the intervention. To avoid this problem, outcomes such as usefulness, application of content, ease of use and acceptability of the booklet were deemed the best measures of effectiveness of the package. The author expected that the package would increase caregivers' level of knowledge of Alzheimer's disease and behaviour management stategies that they could use in their daily living.

3.2.1 Evaluation Tools

The literature was searched for a standardized measurement tool to evaluate the perceptions of usefulness, applicability, ease of use and acceptability of style of the resource booklet. However, no standardized measurement tools were found.

Measurement of knowledge alone was not seen to be a valid measure. Research in this area was discussed previously. As Oberst (1989) pointed out, objective tests of knowledge fail to assess the extent to which the individual can integrate the information. Testing recall is not as effective as evaluating the perceived ability to apply the knowledge to real problems and to the kinds of situations the caregiver is likely to encounter. Hence, the questionnaire design focused on teasing out whether the caregivers perceived that the information was useful to him/her in managing daily situations, not on whether the caregiver could repeat the information in the booklet.

Two stages of evaluation were planned. Phase one (Time 1) took place shortly after (within one week) the caregiver read the resource. Evaluation was conducted using a questionnaire which the caregivers completed in their homes. The purpose of the questionnaire was to measure the caregivers' perceptions of the resource.

The second phase (Time 2) took place within 4-6 weeks following the reading, when a follow-up telephone interview was made to inquire whether the caregiver felt that the content continued to be useful and applicable. The purpose of this second phase was to confirm consistency in perceptions. The evaluation tools, that is, written questionnaire and the telephone interview were designed and pre-tested with other caregivers. In addition, the author sought the expert opinion of two professionals in social work and health sciences to review the questionnaire and telephone interview tool. The revised questionnaire used for the evaluation is found in Appendix C. The final version of the telephone interview used in Phase 2 of the evaluation is found in Appendix D.

3.2.2 Study Population

Caregivers of individuals with Alzheimer's disease were recruited from the VON Caregiver Support Program. A convenience sample of ten was established. The caregivers used in the initial evaluations were excluded from the final evaluation. The approval of the VON Research and Ethics Committee was sought and granted. A letter from the Executive Director (Appendix E) was sent to caregivers asking about their willingness to participate in the project. Following their verbal agreement to receive a call from the author, each caregiver was telephoned and met with the author to discuss the project in more detail. Each caregiver signed a consent form (Appendix F) that acknowledged his/her willingness to read the resource and participate in the two phases of the evaluation. At the time of obtaining consent, it was explained that there was no obligation to participate and that their access to care and services was not dependent on their decision to participate or not.

In the best of all possible worlds, it would have been ideal to have someone other than the author ask for consent to participate. The existence of a third party would have ensured that the caregiver did not feel obligated in any way. The author acknowledged this issue and was careful to explain to each caregiver that he/she had the option to refuse to participate at any time during the study period. It was acknowledged that these caregivers face daily stress in their lives and the author hoped to not place undue hardship on any caregiver.

CHAPTER 4

RESULTS OF THE EVALUATION

4.1 Description of the Study Population

The study population was a convenience sample of ten caregivers selected by the Manager of the Caregiver Support Program to be approached to participate in the evaluation of the learning resource. None of the caregivers was known to the author, nor did the author participate in the selection process. In total, thirteen caregivers were approached and their permission to participate was sought. Two refused to participate stating that they did not have time. One caregiver who initially had agreed to participate, dropped out before completing the questionnaire.

There were four questions in the questionnaire which inquired about background information. This background information was limited to identifying whether the caregiver was male or female; the relationship of the caregiver to the individual with Alzheimer's disease; the caregiver's age; and the length of time of the caring experience. Table 4.1 summarizes the background information.

Caregivers were predominantly female (7 out of 10). The majority (6) of caregivers were looking after a spouse.

The remaining four caregivers were caring for a parent. The women caring for parents reported verbally that each was involved in work outside the home and/or were managing their own families. Two women caring for husbands with Alzheimer's reported verbally that they were working outside the home because of financial difficulties.

The range in age of the caregivers was from under 25 years to more than 74 years. The majority (6) reported being middle-aged. Of the three male caregivers, all reported verbally that they were retired. One of the caregivers identified that he had taken an early retirement in order to look after his wife.

Two caregivers reported being in the "34 and under" age group. One of these women was under 25 years of age. Both caregivers were caring for parents in their own homes. The majority (6 out of 10) of the caregivers had between 3 and 6 years of caregiving experience. Only one caregiver reported being relatively "new" in the role, that is, having less than one year experience.

4.2 Caregivers' Perceptions of the Resource Booklet

The questionnaire was divided into four main sections to gather information on caregivers' reactions to the booklet. First, there were questions about format, second, content, third, usefulness and application and fourth, overall reaction.

4.2.1 Perceptions on Format of the Resource Booklet

The first section of the questionnaire addressed the perception of preference for learning independently. Table 4.2.1 summarizes the caregivers reactions to the format of the booklet. Most caregivers (6 out of 10) responded that they preferred to learn in ways other than learning on their own. At the time one evaluation (one week post-reading), the stated preference was group or class learning. However, at the time two evaluation (4-6 weeks post-reading), the majority (9 out of 10) stated that reading this resource booklet on their own suited them. It cannot be assumed that independent learning had become a "preferred style" because the questions on the questionnaire and telephone interview addressed two different issues. In the questionnaire, the question identified "usual preferred style", whereas the telephone interview asked "does this style suit you".

In the questionnaire caregivers were asked for their perceptions about four other areas concerning the format of the resource. These areas were: the pace of learning, the use of illustrations to highlight ideas, the size of print and the "Reflection Time" pages at the end of each section.

Table 4.2.2 summarizes the caregivers' response to each of these areas.

Pace of learning was perceived as "okay" by six of the caregivers. Reactions to the use of illustrations received more positive response. Most caregivers (7 of 10) responded that the illustrations drew their attention to the ideas.

The size of print used in the booklet was rated as "just right" by all caregivers. In the telephone interview, caregivers confirmed that the size of print had helped to make the booklet easier to read.

Lastly, only six caregivers described the "Reflection Time" pages as useful. The remaining caregivers described these pages as "useless" (2) or indicated that they had not bother to look at them.

4.2.2 Responses to the Content Areas of the Booklet

For each section of the booklet, caregivers were asked to comment on the amount of information presented. The four sections in the resource booklet were: "Alzheimer's Disease", "Managing Day by Day", "Handling Difficult Behaviours" and "Taking Care of Yourself". Table 4.2.3 summarizes the caregivers' reactions.

The majority of the group reacted positively that the content areas contained enough information to meet their learning needs. However, some caregivers wrote comments on the questionnaire to identify where additional information needed to be included. In the section on "Alzheimer's Disease" there was a suggestion to add more information on the urgency of obtaining power-of-attorney in the early stages of the disease. Another caregiver suggested that the information was too focused on Alzheimer's disease and did not address other types of dementia.

In the section on "Managing Day by Day", one caregiver commented on the need to include other reference materials. Another caregiver suggested that ways to handle violent behavious at night should be included. Caregivers' suggestions of additional information to be included in "Handling Difficult Behaviours" included locking away cleaning materials and knives, and considering placement early in the disease process. One caregiver commented that the information was an overview and that it was difficult to include all nuances of behaviours that individuals might present.

Finally, one caregiver wrote a suggestion that specific information be added to the section "Taking Care of Yourself". This caregiver had experienced frustration in not being able to access home care services because her mother's needs did not meet the admission criteria of the Home Care Program. She also wrote on the questionnaire about frustrations experienced by caregivers when other family members refused to accept the diagnosis of Alzheimer's disease. These two areas, accessing the Home Care Program and dealing with other family members were suggested as content to be added to the booklet in future revisions.

4.2.3 Perceptions of the Usefulness and Application of the Content

In the questionnaire, caregivers were asked to give their opinions on how useful the ideas were to their caregiving situations. There were three areas to which the caregivers were asked to respond. First, they were asked "was the information helpful?" The second question asked, "would the caregiver change behaviours based on the information?" Third, the caregivers were asked "were there other methods in their past experience which were more useful than the one presented in the booklet?"

Table 4.2.4 presents the responses of whether the content areas were perceived to be helpful or not. The caregivers gave their response on a 5-point Likert scale. Perceived helpfulness was inferred by the author as the degree of usefulness perceived by the caregiver. The most useful areas, in the caregivers' opinions, were descriptions about and suggestions for handling their own feelings. On the Likert scale, all of the caregivers responded in the 4 and 5 category.

Suggestions for handling difficult behaviours and identification of community resources were rated 4 to 5 by eight of the caregivers. Information on memory loss and reasons for difficult behaviours were rated 4 to 5 by seven caregivers. Ideas for handling daily problems were rated 4 to 5 by only six caregivers. Two caregivers rated four of the items as less than helpful; that is, a rating of 2 on the Likert scale.

The 5-point Likert scale was used to describe the caregiver's opinion on whether he/she would change behaviour as a result of learning the information presented in the booklet. Caregivers were asked to identify their response on the Likert scale as: had no impact (1); intend to change what I do (3); or changed what I do (5). Results of their responses are presented in Table 4.2.5.

The responses to perceived application of content showed that most of the caregivers would apply or had already applied the information. Two content areas were not perceived as applicable as the others. Information on memory loss was rated by half of the caregivers as having little or no impact. Suggestions about daily problems were rated by four caregivers as having had little or no impact on their behaviour.

The information most highly rated as applicable was the content area dealing with caregivers' feelings. Nine caregivers responded that they intended to or had changed their behaviour.

At time 2, the follow-up telephone interview, caregivers' perceptions of the usefulness of the information was reviewed. Responses to the telephone interview are presented in Table 4.2.6.

Seven caregivers confirmed that the resource was useful in their caregiving experience. Six caregivers stated that they had used some of the suggestions in the booklet. Caregivers were asked during the interview to give examples of specific information that had been used. These were related to making the home secure, helping with daily activities such as dressing and bathing, taking care of yourself, managing the behaviours, dealing with guilt, understanding behaviours that were not the fault of the person with Alzheimer's disease and making contacts for future placement.

Finally, caregivers were asked in the telephone interview whether they had gone back to the resource booklet. Two stated that they had not. Six had referred to the booklet "a few times", and two had used it again "only once". Caregivers who had referred to the resource after the initial reading commented that they re-read the section on attitudes or feelings and the section on managing behaviours.

4.2.4 Perceived Reactions to the Resource Booklet

Caregivers were asked to respond to six statements by indicating whether they agreed, disagreed or were unsure of a reaction. The statements reflected their perceptions on usefulness of the information, understanding of the disease, new learning acquired, feelings towards caregiving, skill acquired and whether they would recommend or give the resource to someone else.

The responses to this section of the questionnaire are outlined in Table 4.2.7. Generally, the caregivers' perceived reactions to these statements were positive. The majority agreed with statements regarding usefulness, understanding, new learning acquired and feelings towards caregiving. However, only six caregivers agreed with the statement that the booklet information increased skill in caregiving.

The questionnaire results showed that there was unanimous agreement that the resource would be given to someone else, such as a family member. However, in the telephone interview 4-6 weeks after the reading, only half of the caregivers had actually given the booklet to someone (refer to Table 4.2.6).

Caregivers were also asked to identify what additional information would be helpful in caregiving. Their responses are presented in Table 4.2.8. Being in a support group was valued most highly by 7 of 10 caregivers. Responses were neutral to other sources of help such as attending education sessions, having another caregiver to talk with and getting more community help.

There was space provided on the questionnaire for the caregivers to identify specifically what they would find helpful. Three caregivers wrote that having financial advice, participating in research and continuing to gather as much information as possible, were the additional areas that would help them in caregiving.

Finally, an overall reaction to the booklet was sought in the questionnaire and validated in the telephone interview. There were three categories available for the caregiver to check on the questionnaire. These were: "Wow, I loved it", "It was okay," and "I learned nothing". On the questionnaire, six caregivers checked the response, "It was okay". One caregiver checked that she had learned nothing new; that is, the booklet was of no value to her.

In the follow-up telephone interview 4-6 weeks post-reading, the reaction to the booklet was sought from the caregivers. At that time, nine caregivers rated the resource as "excellent" and one rated it "okay". This latter response was gathered on a 5-point Likert scale.

4.3 Discussion

First, the sample size was so small that the results can only suggest patterns. Second it is acknowledged that the author's involvement in the design, implementation and evaluation of this project may have affected the outcome. Caregivers who participated may have felt the need to please the author. Third it is recognized that survey research is affected by the tendency of some respondents to give consistently high or low ratings. All of these factors must be considered in analyzing the evaluation results.

The author met with each caregiver at the outset of the study to introduce the objectives and ask for agreement to participate. In these face-to-face encounters, each caregiver talked at length about his/her experience in caregiving. Many cried openly and described their own illnesses, some of which were related to the stresses of caregiving. Although most caregivers had supportive families, many explained that they were hesitant to ask family members for help. Six of the caregivers were looking after spouses and were reluctant to involve or burden grown children. Of the four caregivers looking after a parent, only one was unable to obtain support from siblings.

The ratio of female to male caregivers found in this study population (7 females to 3 males) is similar to findings in Cantor's study (1983). Women predominate in the caregiving role, whether as spouses or as daughters or daughters-in-law caring for a parent.

With the majority of the study population having 3-6 years experience in caregiving, it is likely that this past experience influenced the way the caregivers evaluated the booklet. The majority of caregivers were knowledgeable about the disease and skilled in caregiving. The resource was not as useful to them as it would have been to someone new to the role. Most of these caregivers had attended education sessions given by the Alzheimer's Society, had read books about Alzheimer's disease and had attended support groups. This information was not elicited through the questionnaire responses but became known when the author went to visit each caregiver to collect the questionnaires. Caregivers who identified themselves as being knowledgeable stated that they attempted to read the booklet as if they were in an early stage of caregiving in order to provide feedback on its usefulness and application.

The results of the study highlighted the previous knowledge held by many of the caregivers. For example, the caregivers' reaction to question on whether the pace of learning was adequate was described as "okay" by only six individuals. Pace of learning is a personal preference which is influenced by previous education and attitude towards learning. However, the reaction to "pace" may have also been influenced by the majority of caregivers having had previous learning and skill and thus the booklet did not provide as much new material or as much stimulation to learn.

The responses to the question on the use of "Reflection Time" pages may have reflected the group's lack of previous experience with this concept. If these individuals did not have previous experience with this technique, then they would find difficulty using the "Reflection Time" opportunity. The intent of "Reflection Time" was to provide an opportunity for the learner to write some thoughts and feelings in reaction to each section. It is interesting that only one caregiver actually perceived the usefulness of the "Reflection Time" in the intended way.

Caregivers' reactions to the content presented in the sections on handling difficult behaviours or memory loss, or handling daily problems, are in keeping with their stated length of experience. However, the caregivers' positive reaction to the information on dealing with their own feelings was interesting. Given the extent of the caregivers' stress and burden, it is not surprising that they valued information on handling feelings of anger or guilt. As reported by Cantor (1983) and Zarit (1986), the experience creates tremendous strain on caregivers who face many challenges daily as the illness progresses. Trying to maintain an emotional equilibrium is impossible in such circumstances. It is laudable that these caregivers recognized their need for information to help them understand and deal appropriately with these feelings.

Independent learning did not meet the needs of this group of caregivers, even though they said they valued it. As shown in the results, these participants wanted to be involved in support groups where they could receive feedback and know that their burden was shared by others.

This booklet was used only by English speaking Canadians who were literate. It was unfortunate, with respect to the study objectives that the majority of the group was experienced in caregiving prior to the introduction of this booklet. An ideal situation would have been to test the booklet on a group of relatively new caregivers. However, as previous studies (Stone et al, 1987) have shown, caregivers tend to use community resources late in their experiences. Caregivers are difficult to reach earlier in the disease process, since many caregivers deny the diagnosis, thus impeding them from seeking help earlier.

As reported previously, the stress experienced by all of the caregivers was evident. Some reported that spouses were prone to outbursts of violent behaviour (catastrophic reactions) and that this was not only frightening but threatening. The only alternative for these women was to place the spouse outside the home, which created a sense of failure and guilt. Some reported being supported by family members, while some did not. Lack of family support antagonizes the caregiver and adds tremendously to their responsibilities and to their feelings of isolation.

All the caregivers recommended that the booklet be made available to new caregivers. They suggested that the resource be placed in physicians' offices and given to caregivers when the diagnosis is first made. Some reported that they tended to deny the diagnosis and refused to become informed. These people said that reading a resource booklet such as this might be more reasonable as a first stage in recognizing and accepting the diagnosis.

All reported that they could read the resource easily. It did not take a great deal of time, items could be found easily, and the layout and language helped in understanding the ideas. They were positive about the use of medical language in the booklet. Several caregivers said they could now label a behaviour. Labelling was seen as useful perhaps because it decreased ambiguity and uncertainty in recognizing and understanding the behaviours.

4.4 Conclusions

The booklet seemed to be well accepted by the study group. However, the small sample size with relatively experienced caregivers makes it difficult to generalize the results. Nevertheless, as suggested by Gilleard (1990), as the number of books for carers increases, so does the need to evaluate their contribution to patient care.

TABLE 4.1

BACKGROUND OF STUDY POPULATION

BACKGROUND OF RESPONDENT	N
SEX:	
Male	3
Female	7
CARING FOR:	
Wife	3
Husband	3
Mother	3
Father	1
AGE GROUP:	
< 25 years	1
26 - 34 years	1
35 - 44 years	1
45 - 54 years	2
55 - 64 years	2
65 - 75 years	2
> 75 years	1
NUMBER OF YEARS AS CAREGIVER:	
< 1 year	1
1 - 2 years	2
more than 2, less than 3 years	1
3 - 4 years	4
more than 4, less than 5 years	1
5 - 6 years	1
> 6 years	0

(N = 10)

TABLE 4.2.1

PREFERRED LEARNING STYLE

	ITEM	N
TIME 1 QUESTIONNAIRE (1 week post-reading)	Do you prefer to learn on your own?	YES = 4 NO = 6
TIME 2 TELEPHONE FOLLOW-UP (4-6 weeks post-reading)	Looking back, can you tell me whether the format of learning, (ie. by reading the package) suited you?	YES = 9 NO = UNSURE= 1

(N = 10)

TABLE 4.2.2

ACCEPTABILITY OF FORMAT OF THE RESOURCE BOOKLET

ITEM	RESPONSE	N
Pace of Learning	Great Okay Too Slow	4 6 0
Usefulness of Illustrations	Added Nothing Helped to Emphasize Did Not Affect Me	0 7 3
Size of Print	Too Small Just Right Too Large	0 10 0
Usefulness of "Reflection Time"	Useless Helpful Did Not Look At Them	2 6 2

(N = 10)

TABLE 4.2.3

RESPONSES TO THE "CONTENT AREAS" OF THE RESOURCE BOOKLET

CONTENT AREA	RESPONSE CATEGORIES	RESPONSES (N = 10)
Alzheimer's Disease	Too much information	
	Enough information	8
	Not enough information	2
Managing Day by Day	Too much information	
	Enough information	8
	Not enough information	2
Handling Difficult Behaviours	Too much information	
	Enough information	7
	Not enough information	3
Taking Care of Yourself	Too much information	
	Enough information	9
	Not enough information	1

TABLE 4.2.4

USEFULNESS OF "CONTENT AREAS"

"CONTENT AREAS"	DEGREE OF PERCEIVED USEFULNESS				
	NOT HELPFUL (1)	(2)	(3)	(4)	VERY HELPFUL (5)
Information on Memory Loss		2	1	2	5
Suggestions about Daily Problems		2	2	1	5
Reasons given for Difficult Behaviours		2	1	2	5
Suggestions for Handling Difficult Behaviours		2		2	6
Descriptions of Caregiver Feelings				4	6
Suggestions for Handling Caregiver Feelings				4	6
Suggestions about Community Resources			2	2	6

(N = 10)

TABLE 4.2.5

APPLICATION OF THE "CONTENT AREAS"

CONTENT	DEGREES OF PERCEIVED APPLICATION				
	Had no Impact (1)	(2)	Intended to Change what I do (3)	(4)	Changed what I do (5)
Information on Memory Loss	1	4	1	2	2
Suggestions about Daily Problems	2	2		5	1
Reasons given for Difficult Behaviours	1	2	3	3	1
Suggestions for Handling Difficult Behaviours	1	2	4	2	1
Descriptions of Caregiver Feelings		1	2	5	2
Suggestions for Handling Caregiver Feelings		1	4	2	3
Suggestions about Community Resources	1	1	4	3	1

(N = 10)

TABLE 4.2.6

RESPONSES TO TELEPHONE INTERVIEW: TIME 2

ITEM	RESPONSE
1. Was resource useful?	"YES" - 7 "NO" - 3
2. Have you used the ideas?	"YES" - 6 "NO" - 4
3. Did the format suit you?	"YES"- 9 "NO" - 0 "UNSURE" - 1
4. Have you gone back to the resource for information?	"YES" - Only once - 2 - A few times - 6 - Frequently - 0 "NO" - 2
5. Have you given the resource to family to read?	"YES" - 5 "NO" - 5
6. Rate the resource on a 5 point scale	"POOR" - 0 "OKAY" - 1 "EXCELLENT" - 9

TABLE 4.2.7

AGREEMENT WITH THE DESCRIPTIVE STATEMENTS

STATEMENT FOCUS	NUMBER OF CAREGIVERS IN AGREEMENT		
	AGREE	DISAGREE	UNSURE
USEFULNESS	9	1	
UNDERSTANDING	9	1	
NEW LEARNING	9		1
FEELINGS	8		2
SKILL	6	1	3
GIVE TO OTHERS	10		

(N = 10)

TABLE 4.2.8

OTHER PERCEIVED SOURCES OF HELP TO CAREGIVER

ITEM	N
ATTENDING EDUCATION SESSIONS	4
BEING IN A SUPPORT GROUP	7
HAVING ANOTHER CAREGIVER TO TALK WITH	5
GETTING MORE COMMUNITY HELP	5

NOTE: On this area, caregivers could select all the items that applied, hence the variation in N

CHAPTER 5

IMPLICATIONS AND RECOMMENDATIONS

5.1 Implications

The caregivers generally gave positive feedback on the format, usefulness and application of the learning booklet. However, the sample size was too small to allow generalization. It also became clear in the course of the study, that the study group already held a fair degree of knowledge and skill in caregiving. Therefore, the resource did not provide these people with a new learning experience. Nevertheless, the study group did perceive the booklet as helpful.

In order to discover the real value of this booklet, it would be desirable to give it to relatively inexperienced caregivers and to seek their perceptions of its usefulness. The problem of assembling a group of new caregivers is that, caregivers tend to remain independent of community resources and the health care system in the early stages of coping. It is only when the stress of caregiving becomes overwhelming that caregivers tend to seek out resources and assistance.

This evaluation focused only on using the booklet with caregivers. Since nurses and visiting homemakers functioning as respite workers tend to the needs of the client with Alzheimer's and their caregivers, it might be feasible to use the booklet as one component of an education program for these two groups. There is support from the Visiting Homemakers Association in Hamilton-Wentworth to use the resource with this group of workers. VON Canada had also expressed interest in having the resource available for nurses to heighten their awareness of the complexities of caregiving.

Should the booklet be evaluated in a larger study using new caregivers, and if the resource is confirmed with respect to usefulness and application, then it would be advantageous to translate the booklet into other languages. Typically, patient education materials and resources are developed primarily in English or French in Francophone areas and Quebec. There are limited materials in other languages, for example, Italian, Portuguese, Vietnamese, or Polish. Caregivers of different cultural background need written materials in other languages which address their learning needs and use culturally-familiar examples that can be applied.

There may also be caregivers who are functionally illiterate. The booklet is essentially useless if it cannot be read. All caregivers in the study were able to read and thus testing it with the illiterate did not occur at this time. The method of testing the booklet with caregivers who are unable to read would have to be done through a third party. That is, someone able to read the "content areas" such as a child reading to a parent. Designing a different method of learning would be another alternative. That is, presenting the content in a medium other than the written word, such as audio tapes, videotapes, or group meetings.

5.2 Recommendations

Based on the findings of the study, it is recommended that:

i) the resource be revised in light of the comments received from the study group,

ii) another evaluation be undertaken to test the usefulness and application of the booklet,

iii) a larger sample of caregivers new to the role be the focus of the evaluation,

iv) the resource be given to physicians, for example, family physicians, geriatricians, psychogeriatricians and that this group be asked to give the resource to new caregivers. This recommendation was made by 80 percent of the caregivers in the study,

v) the resource be given to visiting nurses and visiting homemakers. The fact that the resource can be read independently is important to this group.

vi) the resource be translated into the languages of recent immigrants. A few of the examples and illustrations may require change to reflect cultural differences. The translation into another language might become a project for heritage language classes.

vii) the booklet be given to the Halton-Wentworth Alzheimer's Society for distribution to caregivers. Most of the study group recommended this.

It is worthwhile to design and evaluate the learning resource booklet for caregivers. Health professionals should pursue a variety of ways to educate and assist caregivers in their role. We need to be creative and innovative in reaching caregivers and in providing support and education.

APPENDIX "A"

SUMMARY OF INTERVIEWS WITH CAREGIVERS REGARDING CONTENT AREAS

CAREGIVER #1

Background: Age 62 Years, Female, Wife, Caregiver for 10 Years (Husband has been placed in nursing home).

Most Important "Content Areas":

What is Alzheimer's Diesase - in layman's terms, with pictures.

Understanding the Problems - the specific behaviours that dementia will cause.

Dealing with the Problems - managing smoking, how to manage when the person is obsessive about something.

- write things down to reinforce activities.

Community Resources - list the agencies, look to a friend for support. Putting his name on a list of placement doesn't mean immediate placement, but gives the caregiver some options.

Care for the Caregiver - recognize that you can't do this alone. "You are not alone even though you think you are". Recognize that it's difficult to ask for help. Must "come to grips with the fact that it's okay to take time for yourself". You need to return to the situation "fresher" to deal with the next crisis.

Other Areas - make the household safe. Get power of attorney. Tell the neighbours because they can help if he wanders.

CAREGIVER #2

Background: Age 42 Years, Female, Daughter, Caregiver for 3 Years (Looks after mother in caregiver's home).

Most Important "Content Areas":

What is Alzheimer's Disease - what are the symptoms, what are the behaviours.

Understanding the Problems - what are the physical changes; walking, bowel and bladder control; what is normal?

Dealing with the Problems - give simple instructions; use visual cues, orient to reality. "Get yourself in a routine for your own sanity". Make decisions one at a time.

Community Resources - use friends for support, Alzheimer Society, Placement Co-ordination Service; Adult Day Care; respite.

Care for the Caregiver - take time away from the person. Either the person goes into a respite care, or the family goes away. When you have a young family, you need time for yourself. Involve the family; have family meetings to decide who will do what.

Other Areas - prepare yourself for special events e.g. Christmas. Use a respite worker to do certain tasks with the person. Use the Wandering Persons Registry.

CAREGIVER #3

Background: Age 70 Years, Male, Husband, Caregiver for 5 Years (Wife has been placed in a nursing home).

Most Important "Content Areas":

What is Alzheimer's Disease - it takes a long time to diagnose; there can be frustration with the health care system - no answers, no diagnosis, lack of communication.

Understanding the Problems - hygiene, unwillingness to change clothes to go to bed; wandering in the night.

Dealing with the Problems - provide some "triggers", e.g. "cajole her by saying someone's coming to see you - then she'll get dressed". Know what triggers aggressiveness, stubbornness. Get power of attorney - prevent her from signing outrageous cheques. Hide the car keys; "needed help from the Police but they couldn't do anything". Must go to the Ministry re: licence.

Community Resources - Wandering Persons Registry; use respite e.g. Home Care Program, St. Peter's Hospital, Caregiver Support Program, support group at Chedoke Hospital have been most helpful.

Care for the Caregiver - feelings of isolation, anger, guilt, frustration, depression. Difficulties in other people not understanding e.g. sisters need to relieve the stress. "Respite is most important". Need to learn new skills e.g. cooking.

Other Areas - "don't take her on holidays; it's too confusing for her, even if it's places that are familiar." Caregivers need to be more assertive with health professionals - "let them know what's happening". Need supportive family and friends.

(NOTE: Neither his son nor wife's sisters would acknowledge that she had Alzheimer's disease. When son finally realized the situation, he cried like a baby.)

APPENDIX "B"

SUMMARY OF CAREGIVER COMMENTS IN RESPONSE TO EARLY EVALUATION OF THE RESOURCE

"Your positive comments actually helps the reader to be more positive. Your emphasis on "BE CALM, BE GENTLE" rings through and through the document. Thanks!"

"I read the manual several times and really enjoyed it more and more. Can I keep my copy when you are through with it?"

"Part I & II. Great all round. Part III. Did you intentionally change format? e.g. What Can You Do?"

"The presentation is great - some pages perhaps a little crowded."

"You have produced a very impressive and useful package of information."

"I found the resource information complete and well presented. I could not add much to the comprehensive content."

APPENDIX "C"

QUESTIONNAIRE:
INDEPENDENT LEARNING RESOURCE FOR FAMILIES

QUESTIONNAIRE

The purpose of this short questionnaire is to evaluate the effectiveness of the resource. The learning resource will be changed based on your comments. Your answers will be kept confidential and will not affect the care that you or your relative receives at any time. Would you take a few minutes to complete this questionnaire, once you have finished reading the learning the resource.

Thank you for your help.

FORMAT

1. This learning resource was designed so that each person by him/herself could learn about caring for someone with Alzheimer's disease. **(Indicate your answer by circling the appropriate number.)**

   Do you prefer learning on your own:

   1. NO -- go to next item

   2. YES -- go to question 2.

   If NO, what other way(s) do you prefer to learn? **(Circle all the numbers that apply.)**

   1. in a group/class
   2. with a teacher
   3. by watching a television program
   4. other ________________ (Please specify)

2. Each page of the resource presented one idea at a time. Would you say that the pace of learning was: **(Circle only one number.)**

   1. Great
   2. Okay
   3. Too slow

3. One some pages, there were drawings to highlight an idea. Would you say that these illustrations:

   1. Added nothing to the idea
   2. Helped to emphasize the idea
   3. Didn't affect me one way or the other

4. The size of the print was:

   1. Too small
   2. Just right
   3. Too large

5. At the end of each Part, there was a page called Reflection Time. I found these pages:

   1. Useless
   2. Helpful
   3. Did not look at them

CONTENT

6. **Tell me about the amount of information presented.** For the Section on ALZHEIMER'S DISEASE, was there:

   1. Too much information
   2. Enough information
   3. Not enough information

   If not enough, what else would you like to have added?

   For the section on MANAGING DAY BY DAY, was there:

   1. Too much information
   2. Enough information
   3. Not enough information

   If not enough, what else would you like to have added?

   For the Section on HANDLING DIFFICULT BEHAVIOURS, was there:

   1. Too much information
   2. Enough information
   3. Not enough information

   If not enough, what else would you like to see added?

For the section on TAKING CARE OF YOURSELF, was there:

1. Too much information
2. Enough information
3. Not enough information

If not enough, what else would you like to have added?

____

This NEXT SECTION asks for your opinions on how useful the ideas are to you and whether you can apply the ideas in your role as a caregiver. For these questions, you will need to circle your answer somwhere on the line between 1 and 5. Each end of the line is defined. Please try to answer all parts of each questions. For example:

The poem by Maude Newton was: ______________________________

1 2 3 [✓ 4] 5

not helpful — very helpful

7. The information about MEMORY LOSS in Alzheimer's victims was:

i) ______________________________

1 2 3 4 5

not helpful — very helpful

ii) ______________________________

1 2 3 4 5

had no impact on me — intend to change what I do — changed what I do

8. a) The suggestions made about DAILY PROBLEMS such as grooming, eating, loss of co-ordination were:

i) ______________________________

1 2 3 4 5

not helpful — very helpful

ii) ______________________________

1 2 3 4 5

had no impact on me — intend to change what I do — changed what I do

b) I have found other methods that I used in the past more helpful than these suggestions.

1. Yes

2. No

If yes, please say what methods you use: ________

____

9. The reasons given for some DIFFICULT BEHAVIOURS such as, shadowing, wandering and incontinence were:

i) ____________________________________

1	2	3	4	5
not helpful				very helpful

ii) ____________________________________

1	2	3	4	5
had no impact on me		intend to change what I do		changed what I do

10. a) The suggestions for handling these DIFFICULT BEHAVIOURS were:

i) ____________________________________

1	2	3	4	5
not helpful				very helpful

ii) ____________________________________

1	2	3	4	5
had no impact on me		intend to change what I do		changed what I do

b) I have found other methods that I used in the past more helpful than these suggestions.

1. Yes
2. No

If yes, please say what methods you use: ________

____

11. The descriptions of CAREGIVER FEELINGS were:

i) ____________________________________

1	2	3	4	5
not helpful				very helpful

ii) ____________________________________

1	2	3	4	5
had no impact on me		intend to change what I do		changed what I do

12. a) The suggestions for handling CAREGIVER FEELINGS were:

i) ______________________________

1	2	3	4	5
not helpful				very helpful

ii) ______________________________

1	2	3	4	5
had no impact on me		intend to change what I do		changed what I do

b) I have found other methods that I used in the past more helpful than these suggestions.

1. Yes

2. No

If yes, please say what methods you use: ________

____

13. a) The suggestions about using COMMUNITY RESOURCES were:

i) ______________________________

1	2	3	4	5
not helpful				very helpful

ii) ______________________________

1	2	3	4	5
had no impact on me		intend to change what I do		changed what I do

b) As a result of reading this, I have contacted some of these agencies:

1. Yes

2. No

If yes, please name the agency:

____

REACTION:

Please respond by checking whether you disagree with, agree with or are unsure of each statement below:

		AGREE	DISAGREE	UNSURE
14.	USEFULNESS I feel I can now **use** this new learning.	☐	☐	☐
15.	UNDERSTANDING I have a better understanding **now** of Alzheimer's disease.	☐	☐	☐
16.	NEW LEARNING I learned something I didn't know before.	☐	☐	☐
	The new learning has been: ______________________________ ______________________________			
17.	FEELINGS I feel more **positive** about caregiving.	☐	☐	☐
18.	SKILL This has been **increased** my skill in caregiving.	☐	☐	☐
19.	GIVE TO OTHERS I would **recommend** this resource to another caregiver.	☐	☐	☐

Now that you have completed this resource, what else would be helpful to you in your role as a caregiver? (Circle all the numbers that apply.)

1. attending education sessions
2. being in a support group
3. having another caregiver to talk with
4. getting more community help
5. other ____________________ (Please specify)

20. Overall, what is your reaction to the learning resource?

1. Wow, I loved it.
2. It was okay
3. I learned nothing

Are there any other comments about the resource you would like to make?

____

____

____

This information is strictly confidential. Would you now answer these questions about your situation:

I am:
1. Male
2. Female

I am caring for:
1. My wife
2. My husband
3. My mother
4. My father
5. Other ______________

My present age is:
1. Under 25 years
2. 26-34 years
3. 35-44 years
4. 45-54 years
5. 55-64 years
6. 65-75 years
7. over 75 years

I have looked after my relative for:
1. Less than 1 year
2. 1 to 2 years
3. more than 2 not less than 3 years
4. 3 to 4 years
5. more than 4 but less than 5 years
6. 5 to 6 years
7. more than 6 years

THANK YOU FOR YOUR HELP

APPENDIX "D"

FOLLOW-UP TELEPHONE SURVEY

CODE NO.: ____________________

DATE CALLED: ____________________

FOLLOW UP TELEPHONE SURVEY

PURPOSE:

i) To confirm results of evaluation.

ii) To determine whether caregivers continue to use the learning resource following initial contact.

INTRODUCTION:

Hello Mrs./Mr. ____________________. This is Esther Green calling about the learning resource for caregivers of individuals with Alzheimer's Disease. Do you recall that I said I would call again to ask you a few questions?

Is this a good time to talk with you? (Call another time - if so when would be convenient?)

I will try to use only a few minutes of your time. The questions can be answered by a Yes or No. However, if you want to give me additional information, please do so.

QUESTIONS:

1. Looking back on when you first read the learning resource, would you <u>now</u> say that the resource was <u>useful</u> to you in your role as a caregiver?

    1. Yes

    2. No

2. Have you <u>used</u> any of the ideas in the resource?

    1. Yes

    2. No

    If YES, can you recall which ideas you have used?

    ____

3. Again, looking back, can you tell me whether the format of learning this way ie. by reading the package <u>suited</u> you?

   1. Yes

   2. No

   3. Unsure

4. Have you gone back to the resource to look for information?

   1. Yes

   If YES, how often?: Once only ☐ A few times ☐
   Frequently ☐

   If YES, what section did you refer to in going back to the resource?

   2. No

5. Have you given the resource to anyone else in your family to read?

   1. Yes

   If YES, Why? ______________________________

   2. No

6. On a scale of 1-5, with 1 being poor and 5 being excellent, how would you rate the resource?

   ____
   1 2 3 4 5

Thank you again for taking the time to answer these questions. I appreciate having your comments.

APPENDIX "E"

LETTER

Dear

Esther Green is conducting a study on the use of an independent learning package for Caregivers.

The objectives of the study are:

1. To develop a learning package which will meet the needs of caregivers of Alzheimer's disease.
2. To determine whether the package has relevant information which can be used by caregivers.
3. To determine whether this type of learning style is acceptable to caregivers.

Participation in the study would involve:

° reading the learning package and completing a questionnaire on how useful you found the package to be. A follow-up phone call may also occur after the package and the questionnaire are completed.

A careful review of our caseloads (those individuals receiving services from VON) indicates that you are a caregiver. If you wish to be contacted by Esther Green to receive more information about this study, please complete the enclosed permission form and return it to us. Completing this form does not obligate you to participate, it simply gives VON permission to release your name to Esther Green so you may receive more information. Your decision either to participate or not to participate will in no way affect the services you receive from VON.

Thank you for considering this request.

Sincerely,

Molly Anderson
Executive Director

MA:

APPENDIX "F"

CAREGIVER LEARNING PACKAGE STUDY: CONSENT

I, ______________________________, am willing to participate in the study on the Independent Learning Package for Caregivers. I understand that I will be asked to:

° read the package at my own pace

° answer a questionnaire

° answer a few questions by phone.

I also understand that I can withdraw from the study at any time and that my withdrawal will in no way affect my care or the care of my loved one.

____

Signed

____

Date

APPENDIX "G"

THE LEARNING RESOURCE BOOKLET

Caring For Someone With Alzheimer's Disease

AN INDEPENDENT LEARNING RESOURCE FOR FAMILIES

-by-

ESTHER GREEN

DEDICATION

This learning resource is dedicated to those caregivers who assisted in the writing of the resource by:

.sharing their
experiences,
.describing ways that
were helpful in
dealing with day-to-day
problems, and
.giving ideas about
needed & necessary
content areas

Without their help, this resource could not have been written.

ACCEPTANCE

You have Alzheimer's disease and you're
losing the power to remember - to reason -
to understand, to do the simple tasks we
take for granted:
.to put on a shoe --
.to button a shirt --
.to read a book --
.to remember a face or name.

It's a hard thing to understand -- to
accept...
Perhaps it's been the hardest for me, for
I've lived with you -- but I know -- you can't
help it -- can't act otherwise...

[I must take you as you are and expect --
not more -- but less as the disease
continues to progress.]

By Maude Newton, a caregiver
in Alzheimer's: A Caregiver's Guide and
Source book. H. Gruetzner
John Wiley & Sons, Inc., New York, 1988.

This learning resource has been written for caregivers and family members who have a relative (husband, wife, mother, father, sister, brother) who has Alzheimer's Disease.

It is written to provide you with information about the following:

.What is Alzheimer's Disease?

.How to Manage Day by Day

.Handling Difficult Behaviours

.Taking Care of Yourself

A Selected Bibliography follows. These resources were reviewed in preparation for writing this package.

CAUTION: This learning resource has a great deal of information but does not assume to have all the answers. The resource was written to highlight areas that caregivers said they needed.

For more thorough information, it is recommended that caregivers might also want to read some of the books listed in the Selected Bibliography.

DIRECTIONS TO THE LEARNER

This learning resource is designed to allow you the flexibility to learn this information at your own pace. You can read all the Parts or only those that you want to learn.

At the end of each Part, there is a section named Reflection Time. These sections were written to help you think about the information you have just read, and to encourage you to find ways to use or apply the new learning.

.Read each page carefully.

.Take time to think about the questions for reflection when they occur.

.You can re-read any Part you want to, when you want to, if you find that this is helpful.

.Remember, YOU control the pace for learning!

.Enjoy the learning resource.

- Index -

PART I: **Page No.**

PART II:

PART III:

PART IV:

PART I

WHAT IS ALZHEIMER'S DISEASE?

ALZHEIMER'S DISEASE

What is it?

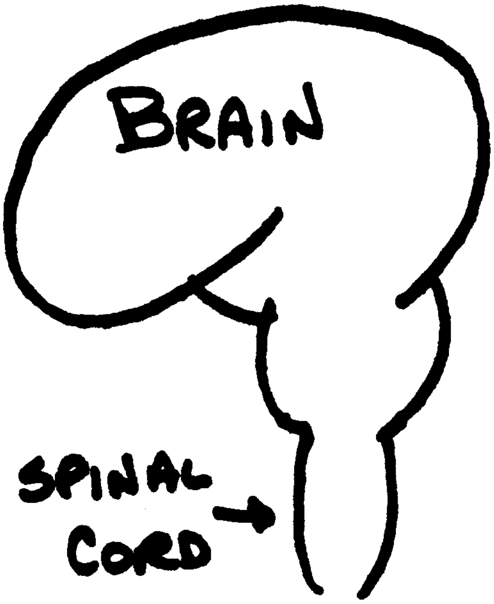
- Alzheimer's Disease is a type of **Dementia.**

- **Dementia** means that there is a <u>loss</u> in the person's ability to think and act normally, even though he/she "seems" normal.

- This is an illness in the brain, which makes the person unable to remember things.

- This disease affects about 300,000 Canadians, those who are middle-aged, and those who are older.

- At present, we do not know what causes Alzheimer's Disease, and doctors don't know how to cure it.



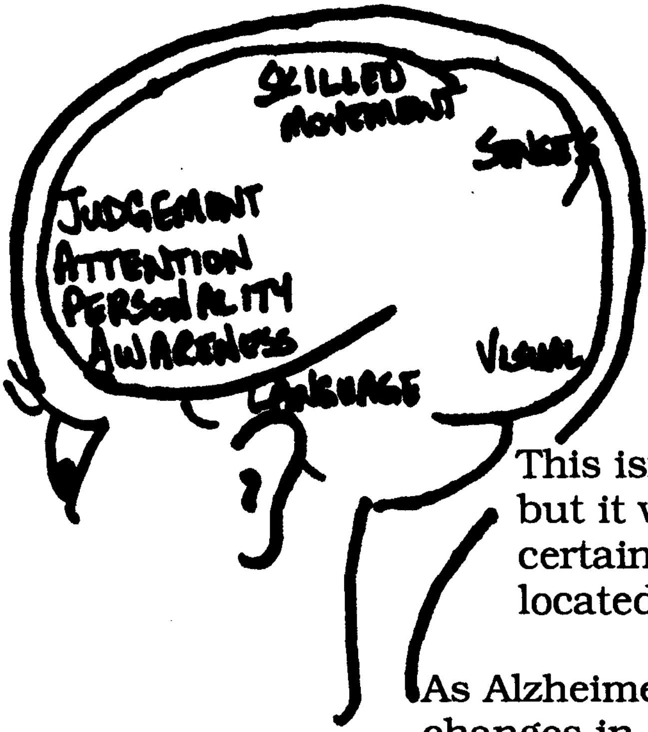
There are changes which occur in the brain.

Slowly, these changes affect the person's ability to think, to behave normally.

At first, the person seems to forget things easily. He/she might become frustrated easily when this occurs.

As we get older, it seems we forget things more easily. Or sometimes when we're under stress, we forget things.

But for someone with Alzheimer's the memory loss becomes worse, to the point where no recent thought seems to stay in their mind.



This isn't a medical drawing, but it will show you where certain "functions" are located in the brain.

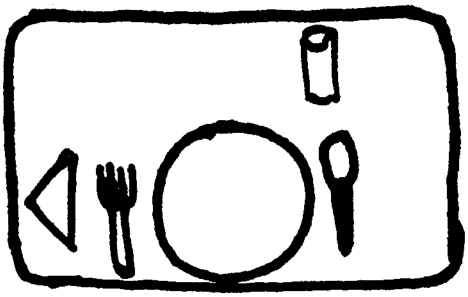
As Alzheimer's disease causes changes in the brain, these "functions" are lost:

What? .ability to answer questions
.ability to speak clearly, use the right words and make sense
4 + 3 =? .ability to calculate numbers
.ability to make a decision

When these losses start, the person doesn't understand what is happening. You may not understand at first either, and this makes both of you confused, and frustrated.

Why?

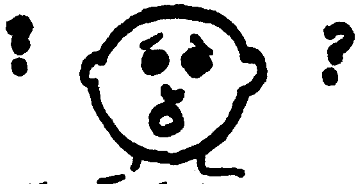
WILL YOU SET THE TABLE?



Even asking the person to do a simple task becomes impossible, as the disease goes on.

For example, the task of setting the table means that the person must:

- .understand the request
- .remember what he/she was asked to do
- .think about the "concept" in his mind



- .organize the task in some order (what do I do first?)
- .remember what comes next (the plate?, the cup?, the fork?)
- .solve any problems (the plates are all in the dishwasher!)
- .know whether this has been successful

Changes for the person with Alzheimer's can happen

SLOWLY

or

quickly

Different Behaviours Performed

Some behaviours that the person with Alzheimer's disease may show are:

.being unfriendly, or angry,

.being tired, unable to do anything,

.being restless,

.being easily upset,

.being afraid

.being sad, crying

.having memory loss,

.being unable to do simple things, such as dressing, eating, going to the bathroom

.seeing or hearing things are not real **(hallucinations)**

.accusing others of stealing things or lying **(suspicious)**

.Not everyone with Alzheimer's disease will act in these ways.

.Some may behave differently than what has been described in this resource.

.Some, who were normally cheerful and friendly, will remain this way.

.All people with Alzheimer's disease will have memory loss.

However, it is IMPORTANT to remember that you and the person with Alzheimer's disease and your family can still enjoy life and each other.

There will be bad times and there will be good times, but always remind yourself that no matter how bad or strange the person is acting, he/she is still a special person; someone you love (that's why you feel guilty sometimes) and someone who loves you.

Different
Stages
And
Symptoms

ALZHEIMER'S DISEASE
MAY OCCUR
IN
THREE STAGES:

1. Beginning symptoms through to Mild Impairment
2. Moderate, increasing impairment
3. Severe impairment

STAGE I

Beginning symptoms through to Mild Impairment

Symptoms:

- .memory loss (names, events) with increasing frequency
- .misplacing things, getting lost - may make excuses or get angry
- .unable to express ideas clearly or understand a request
- .can't seem to concentrate - becomes frustrated easily

What may happen:

- .difficulty in performing a job; friends may wonder why he/she is acting this way
- .person feels very sad, depressed
- .may seek advice from a doctor -- what's happening?

What can you do?:

- .share your feelings with others as much as possible
- .try to keep activities simple
- .develop daily routines, provide cues as to what happens next
- .seek legal advice - now is a good time to assume power of attorney

STAGE 2
Moderate, increasing impairment

Symptoms:

.increasing memory loss
.disorganized thinking
.doesn't know what time it is, what day, month, year, or where he/she is **(disorientation)**
.may wander from home; wakes up in the night
.unable to problem solve; cannot do simple tasks
.losing clear reasonable speech
.may walk "funny" - shuffles feet, unbalanced
.may have mood swings sad stubborn afraid
.occasional incontinence may start

What may happen:

.cannot handle being with others - becomes isolated
.needs 24-hour supervision
.cannot do things such as dressing, bathing, eating without help

What can you do?

.praise the things he/she can do; try not to criticize things he/she cannot do
.make sure he/she has identification, a bracelet, names on clothes
.try to be calm if he/she becomes upset
.look for a support group for yourself e.g. the Alzheimer's Society

STAGE 3

Severe impairment

Symptoms:

.cannot remember people, events, surroundings
.cannot perform normal daily activities
.loses control of bladder and bowel **(incontinence)**
.doesn't make any sense when he/she speaks
.very restless, sees or hears things that are not real, doesn't seem to care anymore
.may be violent, hits out, yells, throws things
.becomes ill due to an infection or illness and dies

What may happen:

.family becomes upset when they are not recognized
.caregiver becomes exhausted trying to give heavy physical care
.person may need to be admitted to a nursing home
.family grieves for their loss - this person is no longer who he/she once was

What can you do?:

.seek short-term and long-term respite - someone else to care for the person
.need to look at the physical and social needs of the caregiver
.talk with family members about what is happening, share your grief, make plans.

MORE FACTS ABOUT ALZHEIMER'S DISEASE

.Alzheimer's disease is NOT contagious, you cannot "catch it" like you catch a cold.

.Alzheimer's usually happens to older people but not everyone who is old will have it.

.Alzheimer's is a disease of the brain, but the person is NOT insane.

.We don't know what causes the disease and we don't know yet how to cure it. Research is being done now to find out the cause.

.Both men and women can be victims of Alzheimer's disease.

.Alzheimer's disease produces decline in the mind and ability to function and eventually the person will die.

.A person can have Alzheimer's disease for as short as 2 years or as long as 14 years.

.During the first and second stage, the person may be able to be cared for at home.

.There is no link to using aluminum pots in cooking to Alzheimer's disease.

.There is no blood test which will show whether someone has it.

Reflection Time

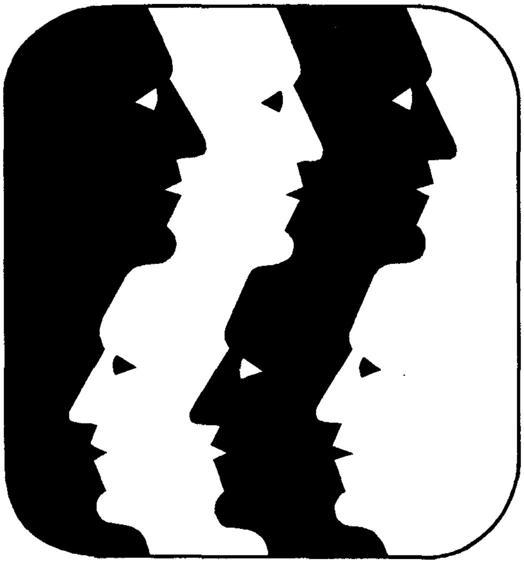
#1

1. Alzheimer's disease is difficult to understand. But now I know that:

2. Sometimes people say "Old-timer's disease" instead of Alzheimer's. I can gently correct them and tell them that Alzheimer's disease is:

3. I know that this is hard on me; but even harder for my relative to accept. To make things easier for both of us, I plan to:

PART II



MANAGING DAY BY DAY

MANAGING DAY BY DAY

PART II, Managing Day By Day is written to describe why certain behaviours happen.

There are some ideas on how you might handle things, and feel okay about what you're doing. These are suggestions. Try things out, and use what works best for you.

Alzheimer's disease is puzzling. The person looks the same, but isn't. It's difficult to see what's going on in their heads -- a broken arm we can see, but Alzheimer's is hidden from our view.

When the person with Alzheimer's acts in a funny way, sometimes the action annoys us. We can become angry, frustrated, confused and feel guilty, all at the same time.

MEMORY LOSS

.at first the person may know that his/her memory is failing

.eventually all memory will be lost

.there are 3 functions of memory:

1. <u>immediate recall</u> - immediately following an event

2. <u>recent memory</u> - recalling events within the day/hour/minutes

3. <u>remote memory</u> - the distant past, months or years ago

.the loss of <u>recent memory</u> leads to problems of:

fear - what's happening?
where am I?

denial - This isn't happening to me.
Someone is trying to trick me.

suspicion - someone stole my money.

Let's look at some day-to-day issues that may occur as a result of memory loss.

MEMORY LOSS

.Memory loss is that feeling of not knowing where you are, how you got there or who people are.

Have you ever been in a hurry when you parked your car at the mall? When you are finished shopping, you go out to find your car, and can't remember where it is. This is a frightening, confusing feeling. Eventually, you solve the problem and find your car.

But the person with Alzheimer's will not be able to problem solve and find the car. Every day is like this.

.Memory loss robs the person of his/her past.

.Memory loss can strain the caregiver who must constantly reassure and repeat things.

WHEN MEMORY LOSS OCCURS:

1. the person may deny the problem, make excuses for mistakes, blame others or seem unaware of the loss

   For someone with Alzheimer's, denial is a defense to protect him/her from something frightening.

WHAT CAN YOU DO:

.try to <u>not</u> force the person to face up to the problem

.use reminders, lists, notes to help his/her memory (if the person can read)

.common forgetfulness is embarrassing;
but memory loss is devastating. Try to understand how the person feels.

.use touch, a reassuring hug to comfort the person when he/she seems afraid or confused

.use pictures or other things to help the person recall an event

WHEN MEMORY LOSS OCCURS:

2. the person asks the same questions over and over.

   the person cannot recall what happened; what your answer was to the question.

WHAT CAN YOU DO:

.answer clearly and slowly to the question
.try to face the person when you are speaking
.have the person repeat what you said
.distract the person to another activity
.write down information that the person is asking for
.reassure the person that everything is fine and you will take care of things
.sometimes the person is worried about something else, but cannot tell you what it is. Try to guess/find out what it is.

For example, a person who always asked when her mother was coming for her, really wanted to know that someone would care for her. (Her mother had died years ago.)

WHEN MEMORY LOSS OCCURS:

3. the person mishandles money (gives it away, hides it, gives enormous tips); doesn't pay the bills, accuses you or others of stealing the money; claims the bank manager is handling everything.

WHAT CAN YOU DO:

.be sure there is no truth to the accusations of theft. An older person living alone may be a victim of someone taking advantage.
.assume responsibility for financial matters
.consider seeing a lawyer to arrange for power of attorney and guardianship to protect the person's financial security. Try to do this in the early stage when the person can agree to power of attorney.
.give the person a small amount of money to help him/her feel in control
.contact local businesses to ensure that purchases made have been/will be paid by you

One caregiver arranged with the local grocery store to set up an account. When her husband bought things, he often forgot to pay. That way, her husband could still shop, and the store could receive its money.

WHEN MEMORY LOSS OCCURS:

4. the person always talks about things that happened in the past

Remote memory is usually least affected by Alzheimer's. Things the person can remember from the past makes him/her feel good about himself/herself.

WHAT CAN YOU DO:

.try to spend some time with the person talking about the past **(reminiscing)**

.help the person to distinguish between the past and present. For example, show pictures of the grandchildren when they were small, and compare these to their pictures now.

.patiently, remind the person where he is, what day it is, what time it is, write it out e.g. Today is Monday, February 19, 1990.

.listen

WHEN MEMORY LOSS OCCURS:

5. the person's memory changes from day to day or hour to hour; remembering some things but not others.

It is normal for the memory of people with Alzheimer's to change like this. Some things may be easier to remember. Things that are frightening or unpleasant will be quickly forgotten.

WHAT CAN YOU DO:

.make the most of good days
.look at those things that are easily recalled
.does something you do increase or improve his/her memory?
.it is easier to remember when things are relaxed and quiet for the person
.give praise when things are remembered

WHEN MEMORY LOSS OCCURS:

6. the person doesn't like to be with friends or visitors; wants to stay at home and not see anyone

When you cannot remember things, you cannot talk with other people about usual social chat -- the weather, world politics, sports. In social situations, the person cannot act like other people and feels frustrated and angry. Sometimes the person becomes rude or says hurtful things, when in a situation that frightens him/her.

WHAT CAN YOU DO:

.involve the person in quiet social situations - only one person at a time

.if you have an invitation to a wedding or party, get someone to stay with your relative. He/she will find the event too difficult; you need some time away.

.inform friends and family about the person's illness; ask for their understanding and help.

WHEN MEMORY LOSS OCCURS:

7. the person doesn't recognize familiar persons (family, friends, neighbours), places and things.

The person is losing the ability to recognize things she/he sees. The message from her/his eyes is not received by the brain, because the brain is damaged. This loss is called **AGNOSIA**.

WHAT CAN YOU DO:

.give the person some hints. For example, call the visitor by name before your relative is asked to remember who this is.

.use the object as you name it. For example, show the comb, name it and use it on your hair.

.use old pictures to help the person remember family or friends

.if you need to travel to another city or country, find someone else to care for your relative. Even if the person has travelled there several times before, he/she will become upset, not remembering where he/she is.

PERSONAL GROOMING:

.The person with memory loss may forget that he/she has not washed, etc. for a while

.Bathing can become embarrassing to the person; he/she may not like to be naked, closed in, in a shower with someone else dong the washing

.The person with Alzheimer's disease will eventually lose the ability to care for himself/herself

.Changing clothes and bathing require many decisions to be made. For someone with a damaged brain, this may be asking too much

.The person may be depressed; too sad to care about himself/herself; or he/she may not realize how much time has passed since he/she changed

PERSONAL GROOMING:

WHAT CAN YOU DO:

1. Maintain bathing and grooming at a regular time each day, the time the person used to do it before.

2. Set things up - run the water; check the temperature; get the towels ready; set out the clothes, etc.

3. Use a bathseat to prevent a fall. Use handrails around the tub and a rubber mat in the tub.

4. Don't put too much water in the tub.

5. Offer to give a backrub or scrub to make bathing more relaxing.

6. Be calm and gentle when you help with a bath.

7. Don't worry about bathing every day. An older person's skin can be very dry, and washing daily may increase dryness. Use lotions after bathing.

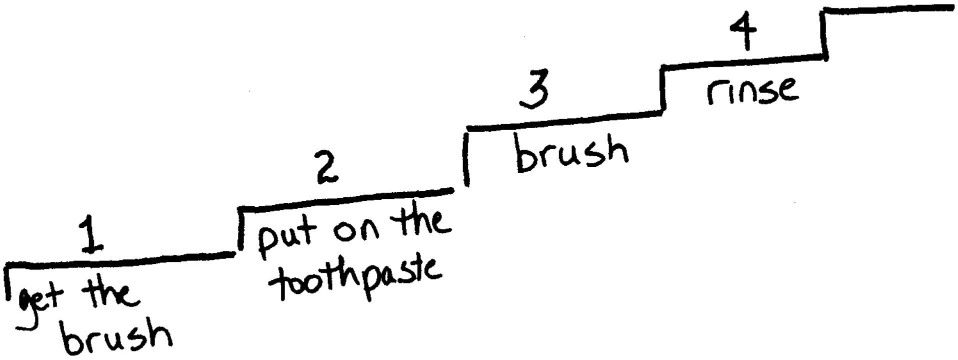
PERSONAL GROOMING:

WHAT CAN YOU DO:

8. Use an electric razor for a man's beard.

9. Try to look for rashes or sores, while helping with the bath. Call your doctor about any unusual sores or redness.

10. To assist the person to brush his/her teeth, remember to break the task into small steps.



If the person is wet or soiled, he/she will need to be cleaned thoroughly to prevent any sores on sensitive skin.

MEALTIMES:

.People with Alzheimer's disease often do not eat properly.

.Sometimes a person forgets that he/she ate, and will ask for food again right after a meal.

.As co-ordination worsens, mealtimes for the person with Alzheimer's will be messy.

.Forgetful people may not remember that they are using a plastic fork and may bite and swallow pieces.

.Hot foods or liquids will be difficult for the person who can no longer judge the heat/temperature.

.Sometimes the person with co-ordination problems may begin to have trouble swallowing.

.In severe impairment (Stage III), the person may stop eating.

MEALTIMES:

WHAT CAN YOU DO:

1. Make mealtime as regular a routine as possible.

2. Involve the person, with simple tasks to do, to help with mealtime.

3. Check dentures to make sure the fit is right.

4. Check the temperature of food and liquids.

5. If the person won't eat certain foods, ask the doctor about supplements and vitamins.

6. If the person is always asking for food, keep yogurt or apple sauce available or other "nibbles".

7. It is easier for the person to handle eating from a bowl rather than a plate.

8. There are ways to alter forks and knives to make them easier to handle; for example, by adding foam taped around the handle.

9. Limit the number of foods you put in front of the person at one time.

10. Don't put salt, ketchup, etc. in front of him/her. Season the food for him/her.

MEALTIMES:

WHAT CAN YOU DO:

11. If you're eating at a restaurant, choose the menu for the person.

12. Serve foods that are easy to eat without help.

13. Try to get the person to drink plenty of fluids during the day.

14. Try to maintain his/her dignity - use a barbecue apron or chef's apron, not a bib.

15. To make clean-up easier, cover the table with plastic, or put plastic on the floor to save the carpet.

16. If you must feed the person, sit on his/her right side (if right-handed) and put the spoon of food where he/she can see it. Touch the spoon gently to his/her lips to remind him/her to eat. Never force food.

17. If choking becomes a problem, you might want to take a Red Cross course on how to handle someone who is choking. **(HEIMLICH MANEUVER)**

LOSS OF CO-ORDINATION

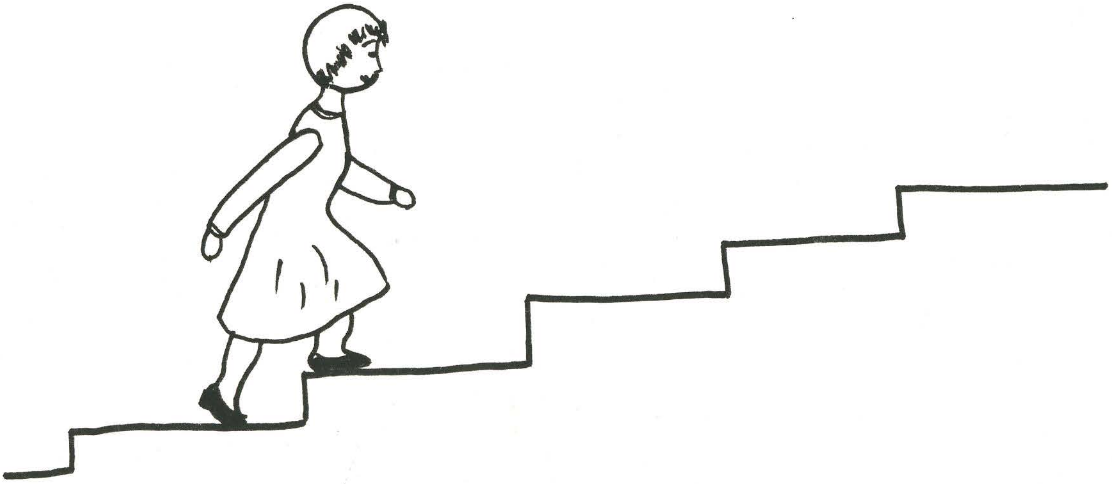
.The person with Alzheimer's may lose the ability to make fingers and hands do certain familiar tasks.

.Later, damage in the brain will affect walking, and the person may be unsteady on his/her feet.

.Loss of co-ordination may lead to problems in daily living, such as bathing, doing up buttons or zippers, dressing, pouring a glass of water, and eating.

.The person may feel tense and embarrassed or worried about his/her clumsiness.

.Sometimes a person can do something one time and not another time.



LOSS OF CO-ORDINATION:

WHAT CAN YOU DO:

1. If the person is unsteady on his feet, you might install handrails, in the bathroom, on stairs or hold on to the person when he is using stairs or stepping onto or off a curb.

2. Try to make each task simple. Instead of saying, "wash your face"; try breaking this down into small steps:
    .turn on the water
    .take the facecloth
    .pick up the soap
    .etc.

3. Try to make the atmosphere relaxed. Do not hurry the person; this makes clumsiness worse.

4. Assist the person with buttons. Or demonstrate/show him/her how to do it or use velcro.

5. Seat him/her in a chair that has armrests. It is easier to rise out of the chair that has supports.

6. Exercise is important. Try to walk with him/her every day.

PROBLEMS WITH COMMUNICATION:

.The problems a person with Alzheimer's has are in:

  i) expressing himself/herself to others and
  ii) understanding what people say to

  him/her

i) .The inability to express oneself, to share feelings, needs, observations and ideas can cause the person to give up or become angry and frustrated.

.Sometimes the person has difficulty finding a word, which is called **ANOMIA.** "I need some ____?____ for my coffee."

.Sometimes the person will use another word that sounds the same - **PARAPHASIA.**

e.g. nurse/purse
mother/wife

or put in a word that has similar meaning.

PROBLEMS WITH COMMUNICATION:

.Sometimes the person will describe an object that he/she cannot name.
e.g. it's a thing that goes around - ring

.Later, the person may be unable to communicate a whole thought but can only express a few words in the thought.
e.g. "bus, home" - meaning: "I want to go home now.

.Some people may ramble on and connect together some common phrases so that what they say, at first, seems to make sense.

.In Stage III, Severe impairment, the person may only remember a few key words.
e.g. "No", which he/she may use whether he/she means it or not.
Eventually, he/she may be unable to speak, may say things that make no sense or cry out off and on.

COMMUNICATION:

ii) Often the person has problems understanding what you and others tell him. Sometimes families think the person just doesn't want to co-operate. Also, with memory loss, the person will quickly forget what you said, even if he/she does understand you.

.Although still able to read, the person may not understand what he/she is reading.

.The brain is unable to make sense out of what is heard.

.People also communicate in the way they use/move their face, eyes, hands and bodies. Even when the person is unable to understand or express himself/herself, he/she may be able to use these actions to express himself/herself.

.Also, the person will "read" your body messages, and may become upset because you "look" angry, even though you're saying that you're not angry.

COMMUNICATION:

WHAT CAN YOU DO:

.when he/she has difficulty finding a word, help him/her by suggesting the word

.if he uses the wrong word, it may be helpful for you to give the right word. But if this upsets him, it may be better to ignore the situation, as long as you know what he/she means

.ask the person to describe what he/she wants, or to point to it

.if you must guess at what he/she's saying, ask him/her if you are guessing correctly

.if the person can still say a few words, ask simple questions, one at a time e.g. Do you hurt? Point to a body part and name it. This way, he/she can nod or shake his/her head in response.

.when the person cannot communicate, you must have a regular routine for checking whether he/she is comfortable. Is the room warm? Does he/she need to eat? Check for rashes or sores on his/her body.

COMMUNICATION: (SPEAKING)

WHAT CAN YOU DO:

1. Make sure the person can hear you. Often, as we age, we may lose some ability to hear.

2. Lower the tone of your voice. A lower tone is easier for someone with hearing loss to hear.

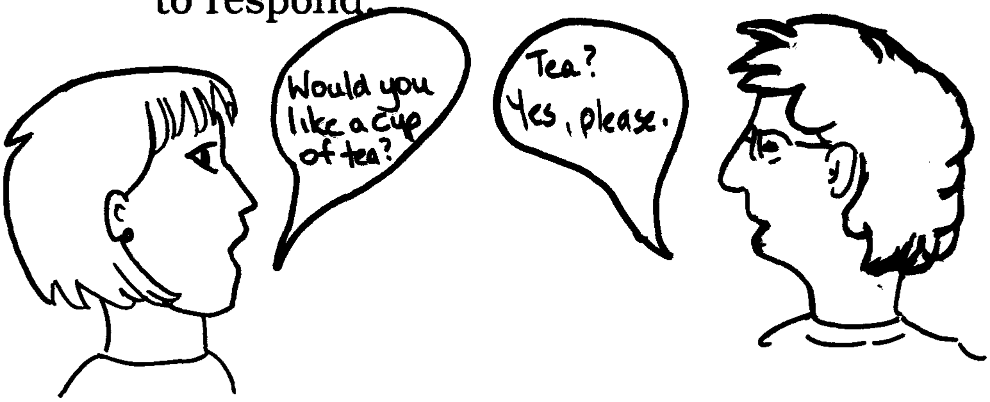
3. Make sure there are no noises or activities which interfere with hearing. e.g. Is the television blaring?

4. Use short words and short simple sentences.

5. Ask only <u>one</u> question at a time. If you repeat the sentence, repeat it exactly.

6. Ask the person to do <u>one</u> task at a time, <u>not</u> several.

7. Speak slowly and wait for the person to respond.



COMMUNICATION: (BODY MESSAGES)

WHAT CAN YOU DO:

1. Stay pleasant, calm and supportive, even if you feel upset. This will help the person to become calm, when he/she is upset.

2. Smile, hold the person's hand, put your arm around him/her -- show affection.

3. Use other signals besides words:
   pointing
   touching
   handing the person something

4. Holding hands, hugging or just sitting together quietly is a good way to communicate.

MANAGING DAY BY DAY

Managing day by day can be

STRESSFUL

for you and your relative.

When the person with Alzheimer's disease feels stressed, he/she may react by shouting, crying, hitting or withdrawing.

The best approach to handling stressful times is to be

CALM ——————

Take 5. Take a deep breath, count to 10.
Try to think about what upset him/her.
Try again - slowly, calmly.
or
Let it go for now.

Reflection Time
#2

1. Sometimes my friends ask what is wrong with my relative. I can tell them that:

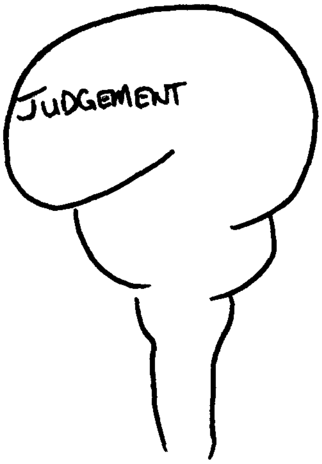
2. When _______ doesn't want to wash or change clothes, I will:

3. I think that the best way to talk with _________ is to:

4. I know that _______ wants to help me with things. I will encourage him/her to do:

PART III

HANDLING DIFFICULT BEHAVIOURS



The changes in the brain that affect memory and judgement also affect other aspects of the person with Alzheimer's disease.

Not everyone will show all of these problems. These behaviours may not occur to the same extent in everyone.

Why?

In Part III, some of these behaviours are described. It will help if you understand why these occur. Then you can decide how to handle these situations.

DRIVING

Driving will be a problem for someone with Alzheimer's disease. With memory loss, the person will become lost easily. With damage to the brain, his/her judgement, ability to think and make decisions will be impaired.

YET, driving is a source of independence. We all want to be able to travel freely, run errands, etc.

One of the difficult decisions a caregiver must make is to take away the person's right to drive. Driving for someone with Alzheimer's is **UNSAFE**. He may harm himself/herself or someone else.

There is no easy solution to the problem of driving. But here are Some Things You Might Want To Try:

.talk to the person about how he/she feels about driving. Does he/she know he/she's unsafe.

.if possible, get him/her to agree to giving up his driver's licence.

.if he won't give up driving, you may need to:

- -HIDE THE CAR KEYS
- -PARK THE CAR WHERE HE CAN'T SEE IT
- -USE ANOTHER METHOD OF TRANSPORTATION

.you might want to ask for advice from your lawyer, local police or Department of Transportation.

SUSPICION

.The person with Alzheimer's is confused and forgetful. He/she does not understand what is happening around him/her.

.When he/she forgets where something is, he/she may say that other people have stolen something, are lying, etc. He/she may even accuse you.

.This is difficult because you feel hurt and angry. You've told him/her where his/her money/keys/glasses are - if only he/she could remember.

SOME THINGS YOU MIGHT WANT TO TRY:

.try to help the person find what he/she's lost, or remember what he/she was told about an issue.

.stay calm. Gently remind him/her of the facts. Find the missing item.

-------**Don't take it personally**---------

SHADOWING

Shadowing is a behaviour that the person may show because he/she is feeling afraid and insecure. He/she follows you everywhere, or watches you all the time. He/she wants to be near you because he/she doesn't like to be alone.

SOME THINGS YOU MIGHT WANT TO TRY:

.Try to spend specific times together every day.

.When you have to go somewhere, tell him/her and write down where you're going, when you'll return. (This depends on whether he/she can read.)

.Try a distracter - involve him/her in another activity.

.It is important that you try to not let this "get to you".

ANGER

Sometimes the person with Alzheimer's disease becomes angry. The person may slam things around, hit you, refuse to be cared for, throw food, yell or make accusations.

This is very upsetting for you and your family. It seems as though all the anger is aimed at you, in spite of everything you've done.

SOME THINGS YOU MIGHT WANT TO TRY:

-try to stay calm
-do not become angry
-understand that the anger is probably a misunderstanding that the confused person interprets
-if these angry attacks continue, contact your doctor for an assessment
-if you can find out what triggered the anger, you may be able to solve the problem

WANDERING

.Wandering is a common and serious problem. The person with Alzheimer's disease can be in danger when he/she wanders from home, because he/she is unable to find the way back.

.Some wander for no known reason.

.Some wander because there have been too many new things introduced.
e.g. a move

.Some wander at night.

.Sometimes wandering is a way of trying to communicate, of showing restlessness, boredom or a need for exercise.

.Something may be upsetting the person.

-- THIS IS NOT A BEHAVIOUR THAT THE PERSON CAN CONTROL --

HANDLING WANDERING

1. Make sure that the person has identification on him/her, such as a bracelet. You can have inexpensive bracelet engraved.

2. Try taking the person for long walks each day. This may reduce the restlessness.

3. It may be helpful to install locks that are unfamiliar to the person. But you must be careful that, in an emergency, such as a fire, the lock can be easily opened to allow for escape.

4. Tell your neighbours about the problem.

5. Talk to the Police. Ask if they have a Wandering Person's Registry.

6. Put signs on the doors in the house:
    .Bathroom
    .Bedroom

7. Use nightlights to show the way to the bathroom at night.

8. If the person wanders at night, try making a warm cup of milk for him/her, comfort him/her, then lead him/her back to bed.

9. If sleeping problems continue, ask your doctor of advice.

SMOKING

Smoking may become difficult for the person with Alzheimer's disease because of forgetfulness and loss of judgement.

The forgetful person can be a danger to himself/herself and others with a lighter, matches or lit cigarette.

SOME THINGS YOU MIGHT WANT TO TRY:

If the person must smoke, make sure that someone stays with him/her while he/she has a cigarette/cigar/pipe.

You need to keep cigarettes and matches in your control; hidden away. Give the person a cigarette at regular times.

INCONTINENCE

People with Alzheimer's disease may begin to wet themselves or soil themselves. This is called **INCONTINENCE.**

When this first happens, ask your doctor to see the person to find out whether there is an infection or other cause.

The person may be incontinent because he/she cannot find the bathroom; or because he/she cannot get there quickly enough.

This may also happen because the person cannot tell you that he/she needs to go to the bathroom.

This is difficult for caregivers. It is upsetting to have to clean up after an adult. But remember, the person cannot control this behaviour.

HANDLING INCONTINENCE

There are many ways you can handle the problem:

1. make a regular routine of taking the person to the bathroom, e.g. every two or three hours.
2. limit fluids in the evening.
3. put a sign on the bathroom door and use a night light.
4. rent a commode - this is a portable chair and pot that can be placed in the bedroom so that the person can use it in a hurry.
5. try to find out what the person's usual pattern is -- such as right after breakfast is the time for a bowel movement. Use that pattern.
6. make going to the bathroom a pleasant experience -- use music, a book to read.
7. accidents may happen, and it is best to accept that.
8. protect the furniture with plastic covers or washable cushions.

DO NOT PUNISH -- IT'S NOT HIS/HER FAULT.

MAKING THE HOME SAFE

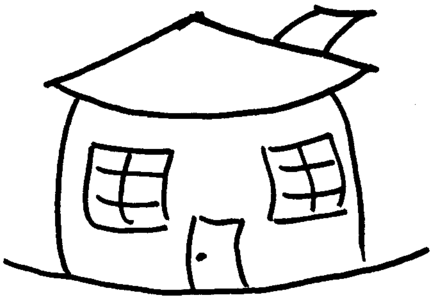
Because the person has lost the ability to think clearly, some dangerous situations might happen:

.fire, due to cigarette smoking or a burner being left on
.burns, due to too hot water
.getting lost at night, in bad weather

You can change the house in small ways that will help to keep things safe:

-use locks that the person cannot handle alone
-lock up all medicines, cigarettes, matches
-have a switch put on the stove that will not let a burner be turned on until the switch is on
-turn the temperature down on the water heater
-take up loose carpets
-use lots of light, nightlights

CAN YOU THINK OF OTHER THINGS TO DO?



GOING TO THE HOSPITAL

There may be a possibility that the person with Alzheimer's becomes sick and needs to go to the hospital.

If this happens:

- .try to stay with him/her
- .tell the doctors and nurses that he/she has Alzheimer's disease
- .tell the nurses what his/her usual routine is and ask them to follow it, if possible
- .ask whether you or another relative can stay in the room during the day and night
- .bring in things that are familiar, such as pictures, books
- .if he/she wears glasses, dentures, hearing aids, or uses a cane, he/she has them and uses them
- .ask for a private room - having someone strange in the room may upset him/her

REFLECTION TIME
#3

1. Being in control of our lives is important to all of us. Right now I feel:

2. When my relative does things that annoy me, I can:

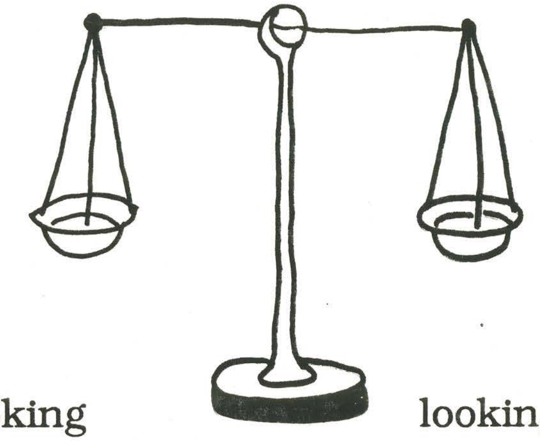
3. I understand, why he/she does these strange things. It's because:

4. When I feel angry/sad/alone/frustrated, I will:

PART IV

TAKING CARE OF YOURSELF

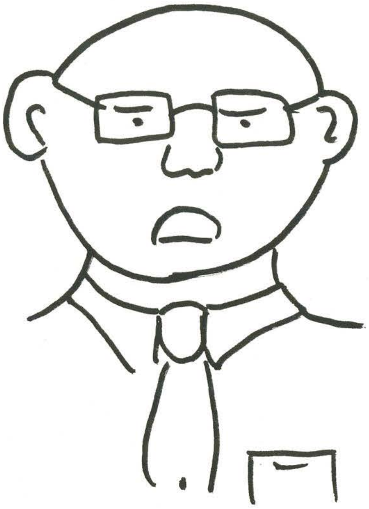
Caregivers must balance
time and energy
spent



on looking after the person with Alzheimer's disease, and looking after yourself.

This is sometimes difficult to balance all the demands placed on you. But you must look after yourself in order to look after the person Alzheimer's disease.

Sometimes caregivers must learn new roles:



a man might
have to learn....
-how to do the washing
-how to cook
-how to keep house
-how to buy clothes
for his wife

a woman might
have to learn....
-how to do the banking
-how to pay the bills
-how to fix things around the house

Trying to do things that you've never done before can be upsetting.

The person with Alzheimer's disease may also be upset to see you do things he/she once did.

RECOGNIZE YOU NEED HELP!

If you are a daughter or daughter-in-law

you may have

...the demands of your job or career to manage

...the children to look after

...the person with Alzheimer's who needs you

...your husband who wants to spend time together

...your own home to manage

It is difficult for one person to manage everything.

You need help - don't hesitate to look for help.

WHAT CAN YOU DO?

You can...

-recognize that caregiving is very stressful

-find out what others can do to help you

-involve your family in decisions you must make for the person with Alzheimer's - **SHARE THE LOAD**

-have family conferences, ask what each person can do to help

-find a support group, other caregivers who are going through this too. (Call the Alzheimer's Society)

-encourage the person to do what he/she can for himself/herself

-make time for yourself - go away for a week-end; go shopping; have a quiet, hot bath

YOU NEED TO LOOK AFTER YOURSELF!

FEELINGS

It is difficult to be a wife, husband, daughter, son, relative or friend of someone with Alzheimer's disease. It can be a long illness during which the person changes - becomes different in mood, behaviour and ability to think and remember.

Caregivers have feelings looking after someone who has changed so much and who demands time and energy.

Some feelings you may have are:

ANGER

GUILT

ISOLATION

SADNESS

What can you do?

ANGER

It is difficult to accept feelings of anger or frustration. You resent having to change the plans you made and look after someone else. This is a NORMAL FEELING.

You can...

.Talk to your friends about how you are feeling.

.Put your anger on paper; keep a diary.

.Go for walks or do some exercise that you enjoy.

.Go to an Alzheimer's family support group on a regular basis. Talk to others about their feelings.

.Try relaxation tapes or exercises.

GUILT

It is common for caregivers to feel guilty: for the way they treated the person in the past; for being embarrassed by the person's behaviour; for losing their temper with someone who is ill; for not wanting this responsibility; for - all kinds of things. THIS IS A NORMAL FEELING!

You can...

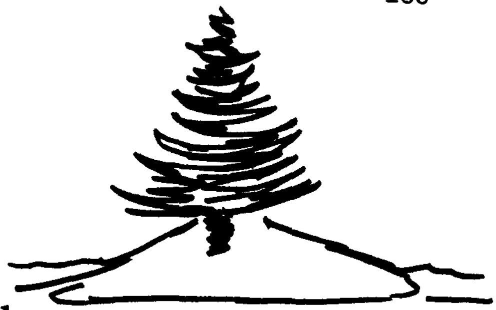
.Recognize that you are not responsible for the fact that this person has Alzheimer's disease.

.Talk to someone you trust about how you're feeling. Talk to your doctor or a nurse or a social worker.

.Go to an Alzheimer's support group.

.Recognize that you are human and can only do so much.

ISOLATION



You may find that it is more and more difficult to see friends, go out for an evening, do the things you always enjoyed because of the behaviour of the person.

But you need to pay attention to your own needs - needs for friends and social times.

You can...

.Use **respite** services - someone comes into your home to stay with the person while you go out. Or, the person goes to an institution for a weekend or while you go on vacation.

.Go out for dinner with friends.

.Go to the library or the mall.

.Have one or two people over for dinner - people who understand.

.Take a course at the high school or community college.

.Don't feel guilty about taking time for yourself.

SADNESS

You may feel sad because you are slowly losing someone you love. You may be sad because the things you planned for the future won't happen for the person.

Sometimes, feeling sad makes changes in us that we need to be aware of:

- a change in eating habits e.g. no appetite
- a change in sleep e.g. being unable to sleep
- a lack of energy
- being unable to concentrate
- changes in mood

If you feel this way, you can...

.Talk to someone - a minister, priest, rabbi, a counsellor, a doctor, a nurse

.Go to a support group - talk to others

.Spend time away from the person - do a hobby, go out for dinner with friend

.Try to get more rest. Fatigue makes you feel worse.

.Use the Community Services - respite services

?? MAKING DECISIONS ??

There are many things that you as a caregiver will need to decide on:

.finances - how will the money be managed?

.job - can I continue to work and be a caregiver?

.living arrangements - where will the person live - my house?
- his/her house?

.power of attorney - it's best to do this early, when the person can agree to you taking power of attorney

.making the house safe - what changes need to be made?

.taking vacations - who will look after the person with Alzheimer's

.arranging for the person to live in a nursing home or chronic care institution - there will come a time when you will no longer be able to provide care

?? MAKING DECISIONS ??

No one can tell you what to do. Each situation is special. It is difficult to make these decisions, but they need to be made.

Involve other people in making the decisions <u>with you:</u>

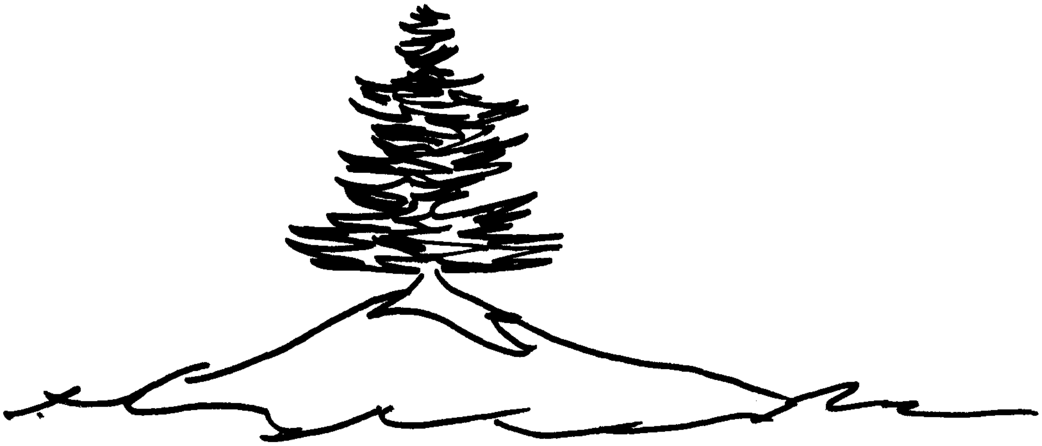
- .your children
- .family - brothers, sisters

Use people in the community to help you:

- .public health nurse
- .Alzheimer's Society
- .community nurse (such as VON or St. Elizabeth Visiting Nurses)
- .physician
- .social worker

They can help too!

Sometimes,
being a caregiver
you feel isolated &
alone.



But,
you are not alone. There
are family, friends, neighbours
and community resources
available to help you.

COMMUNITY RESOURCES

There are lots of people in the community who can help you to give care to the person with Alzheimer's disease.

Some of the Community Resources are:

.VON Caregiver Support Program

This program can provide regular relief in the home from caregiving for up to 20 hours a month; information about dementia and caregiving; help with problem solving.

.Adult Day Programs

These programs offer respite for caregivers by getting the person with Alzheimer's involved in a daily program away from home. Often snacks or a lunch is provided. There are activities available which are suited to the person's needs. Specially trained staff plan the program.

COMMUNITY RESOURCES

.Meals On Wheels Program

This program delivers a hot, nutritious meal at noon, from Monday to Friday. If the person is alone during the day, this could be a way to provide a meal while you're away.

.Placement, Co-ordination Service

The Placement Co-ordination Service helps people of any age to find the right kind of long term care for their relative. This service assesses the person's needs, along with the doctor and nurses, and suggests the best way to meet those needs; e.g. a chronic care hospital, nursing home, home for the aged.

You need to talk about placement with your doctor early. It may take some time until a suitable place is available. Start now. You will also want to see the places yourself, and what they can do for your relative.

COMMUNITY RESOURCES

.Alzheimer Society

This is a charitable group which believes in self help and mutual aid. The Society has branches across Canada, in every province.

The Alzheimer Society provides support for persons with Alzheimer's disease and their families. It supports research into the causes, prevention and treatment of Alzheimer's disease. It provides education and information to families, health professionals and the community.

Regular education session series are held by the Alzheimer Society.

There are also support groups for families that are arranged by the Society.

COMMUNITY RESOURCES

.The Wandering Patient Registry

This is a joint project of the Alzheimer Society and the Regional Police. This allows the Police ready access to information that will help them search for a lost or wandering person.

Registration of persons with Alzheimer's disease is entirely voluntary and costs nothing.

Information about the appearance, behaviour and contacts are registered on a computer with the Regional Police and made available to officers throughout the Region to identify and locate the person.

COMMUNITY RESOURCES

.Public Health Nurses

The Public Health Department has specially trained nurses who can come to your home and talk with you. They can work with your doctor to assist you in planning care for your relative.

.Home Care Program

The Home Care Program can arrange for services to be given in your home, such as:

- nursing
- occupational therapy
- social work
- homemaking
- etc.

if you meet the eligibility criteria. Your doctor must make a referral to the Program. Talk to him/her.

Reflection Time
#4

1. What does your family member expect from you as his or her caregiver?

2. What can your family member reasonably expect from you?

3. As a caregiver what are your 5 most basic needs?

4. How does the caregiving role interfere with having your needs met?

5. What alternatives do you have?

SELECTED BIBLIOGRAPHY

Alzheimer: The Information Kit. Alzheimer Association of Ontario: Toronto, 1988.

Carroll, David. When Your Loved One Has Alzheimer's: A Caregiver's Guide. New York: Harper and Row Publishers, 1989.

Gruetzner, Howard. Alzheimer's: A Caregiver's Guide and Source Book. New York: John Wiley and Sons, Inc., 1988.

Heston, Leonard and June White. Dementia: A Practical Guide to Alzheimer's Disease and Related Illnesses. New York: W. H. Freeman and Company, 1983.

Kociol, Lori and Myra Schiff. Alzheimer: A Canadian Family Resource Guide. Toronto: Mcgraw-Hill Ryerson, 1989.

Mace, Nancy and Peter Rabins. The 36-Hour Day. Baltimore: The John Hopkins University Press, 1981.

Murphey, Cecil. Day to Day Spiritual Help When Someone You Love Has Alzheimer's. Philadelphia: The Westminister Press, 1988.

Oliver, Rose and Frances Bock. Coping with Alzheimer's: A Caregiver's Emotional Survival Guide. California: Wilshire Book Company, 1987.

Powell, Lenore and Katie Courtice. Alzheimer's Disease: A Guide for Families. Massachusetts: Addison-Wesley Publishing Company, 1983.

Safford, Florence. Caring for the Mentally Impaired Elderly: A Family Guide. New York: Henry Holt and Company, 1986.

Springer, Dianne and Timothy H. Brubaker. Family Caregivers and Dependent Elderly. Beverly Hills: Sage Publications, 1984.

REFERENCES

Aronson, Miriam K., Gilbert Levin, and Rochelle Lipkowitz. 1984. A community-based family/patient group program for Alzheimer's Disease. The Gerontologist 24 (4): 339-342.

Brody, Elaine M. 1981. "Women in the middle" and family help to older people. The Gerontologist 21 (5): 471-480.

Brody, Elaine M., Pauline T. Johnsen, Mark C. Fulcomer, and Abigail M. Lang. 1983. Women's changing roles and help to elderly people: Attitudes of three generations of women. Journal of Gerontology 38 (5): 597-607.

Brody, Elaine M. 1985. Parent care as a normative family stress. The Gerontologist. 25(1): 19-30.

Brody, Elaine M. 1986. Filial care of the elderly and changing roles of women (and men). Journal of Geriatric Psychiatry 19: 175-201.

Brody, E.M., M.H. Kleban, P.T. Johnsen, C. Hoffman and C. Schoonover. 1987. Work status and parent care: A comparison of four groups of women. The Gerontologist 27: 201-208.

Brody, Elaine M., Women in the Middle: Their Parent-Care Years. New York: Springer Publishing Company. 1990.

Callahan, Daniel. 1988. Families as caregivers: The limits of morality. Archives of Physical Medicine and Rehabilitation. 69: 323-328.

Cantor, Marjorie M. 1983. Strain among caregivers: A study of experience in the United States. The Gerontologist 23 (6): 597-604.

Christopherson, B., and C. Pfeiffer. 1980. Varying the time of information to alter preoperative anxiety and postoperative recovery in cardiac surgery patients. Heart and Lung, 9: 854-861.

Cohen, Gene D. 1990. Alzheimer's disease: Clinical update. Hospital and Community Psychiatry. 41 (5): 496-497.

Crossman, Linda, Cecilia London, and Clemmie Barry. 1981. Older women caring for disabled spouses: A model for supportive services. The Gerontologist, 21: 464-470.

Doak, Cecilia C., Leonard G. Doak, and Jane H. Root. Teaching Patients with Low Literacy Skills. Philadelphia: J.B. Lippincott Company, 1985.

Eagles, J.M., A. Craig, F. Rawlinson, D.B. Restall, J.A.G. Beattie, and J.O. Besson. 1987. The psychological well-being of supporters of the demented elderly. British Journal of Psychiatry. 150: 293-298.

Ekbert, J.Y., N. Griffith, and M.J. Foxall. 1986. Spouse burnout syndrome. Journal of Advanced Nursing. 11: 161-165.

Gallagher, Dolores, Jonathan Rose, Patricia Rivera, Steven Lovett, and Larry W. Thompson. 1989. Prevalence of depression in family caregivers. The Gerontologist. 29 (4): 449-456.

George, Linda K. and Lisa P. Gwyther. 1986. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist. 26(3): 253-259.

Gessner, Barbara A. 1989. Adult education: The cornerstone of patient teaching. Nursing Clinics of North America. 24 (3): 589-595.

Gilleard, Christopher J. 1990. Self-help information for carers: Does it help? Geriatric Medicine. 13-14.

Gnaedinger, Nancy. 1989. The Alzheimer's household: Who cares for the caregivers? Canadian Medical Association Journal. 141 (12): 1273-1275.

Greene, Vernon L., and Deborah J. Monahan. 1989. The effect of a support and education program on stress and burden among family caregivers to frail elderly persons. The Gerontologist. 29 (4): 472-477.

Gruetzner, Howard. Alzheimer's: A Caregiver's Guide and Sourcebook. New York: John Wiley and Sons, Inc., 1988.

Gwyther, Lisa P. and Mary Ann Matteson. 1983. Care for the caregivers. Journal of Gerontological Nursing. 9(2): 92-95, 110, 116.

Haley, William E., S. Lane Brown, and Ellen G. Levine. 1987. Experimental evaluation of the effectiveness of group intervention for dementia caregivers. The Gerontologist. 27 (3): 376-382.

Haley, William E. 1989. Group intervention for dementia family caregivers: A longitudinal perspective. The Gerontologist. 29(4): 478-480.

Hayter, Jean. 1982. Helping families of patients with Alzheimer's disease. Journal of Gerontological Nursing. 8 (2): 81-86.

Henri, Judy. 1980. An alternative to institutionalization. The Gerontologist. 20 (4): 418-420.

Hiemstra, R. 1976. The older adult's learning projects. Education Gerontology. 1: 331-341.

Hilts, Linda and B. Jane Krilyk. Write Readable Information to Educate. Hamilton: Chedoke-McMaster Hospitals, 1989.

Hooyman, Nancy R. Women as caregivers of the elderly: Implications for social welfare policy and practice. In Aging and Caregiving: Theory Research and Policy, ed. David E. Biegel and Arthur Blum, 221-241. Beverly Hills: Sage Publications, 1990.

Hopkins, R.W. Projections of Dementia. Toronto: Alzheimer Association of Ontario, 1989.

Horowitz, Amy. 1985. Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist. 25 (6): 612-617.

Hussey, Leslie C., and Kathy Gilliland. 1989. Compliance, low literacy, and loss of control. Nursing Clinics of North America. 24 (3): 605-611.

Kahan, Jason, Bryan Kemp, Fred R. Staples, and Kenneth Brummel-Smith. 1985. Journal of the American Geriatrics Society. 33 (10): 664-670.

Kim, Katherine K.1986. Response time and health care learning of elderly patients. Research in Nursing and Health. 9: 233-239.

Knowles, Malcolm S. The Adult Learner: A Neglected Species. Houston: Gulf Publishing, 1984.

Kociol, Lori and Myra Schiff. Alzheimer: A Canadian Family Resource Guide. Toronto: McGraw-Hill Ryerson, 1989.

Laine, Laura, Robert J. Schulman, Kay Bartholomew, Pat Garner, Theresa Reed and Sally Cole. 1989. An educational booklet diminishes anxiety in parents whose children receive total parenteral nutrition. American Journal of Diseases in Children. 143: 374-377.

Lazarus, Richard S. and Susan Folkman. Stress, Appraisal and Coping. New York: Springer Publishing Company, 1984.

Lichtenberg, Peter A. and Jeffrey T. Barth. 1989. The dynamic process of caregiving in elderly spouses: A look at longitudinal case reports. Clinical Gerontologist. 9(1): 31-44.

Lipkin, Laurel V. and Kathleen J. Faude, 1987. Dementia: Educating the caregiver. Journal of Gerontological Nursing. 13(11): 23-27.

Lund, Dale A., Leslie L. Feinhauer and Jean R. Miller. 1985. Living together: Grandparents and children tell their problems. Journal of Gerontological Nursing. 11(11): 29-33.

Mace, Nancy L., and Peter V. Rabins. The 36-Hour Day. New York: Warner Books, 1981.

Mohide, E. Ann, Dorothy M. Pringle, David L. Streiner, J. Raymond Gilbert, Gisele Muir and Michelle Tew. 1990. A randomized trial of family caregiver support in the home management of dementia. Journal of American Geriatrics Society. 38: 446-454.

Montgomery, Rhonda, J.V., and Edgar F. Borgatta. 1989. The effects of alternative support strategies on family caregiving. The Gerontologist. 29(4): 457-464.

Morycz, R.K. 1985. Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. Research on Aging. 7(3): 329-361.

Noelker, Linda S., and David M. Bass. 1989. Home care for elderly persons: Linkages between formal and informal caregivers. Journal of Gerontology: Social Sciences. 44(2): 563-570.

Oberst, Marilyn T. 1989. Perspectives on research in patient teaching. Nursing Clinics of North America. 24(3): 621-628.

Pierce, Linda, Kathy Adler and Patricia Peter. 1989. Caregiver burden and coping strategies. The American Journal of Alzheimer's Care and Related Disorders and Research. 36-41.

Rabins, Peter V., Nancy Mace and M.J. Lucas. 1982. The impact of dementia on the family. Journal of the American Medical Association. 248(3): 333-335.

Regner, Michael J., Freya Hermann and L. Dougles Ried. 1987. Effectiveness of a printed leaflet for enabling patients to use digoxin side-effect information. Drug Intelligence and Clinical Pharmacy. 21: 200-203.

Rice, J. and J. Johnston. 1984. Preadmission self-admission bookets, post admission exercise performance and teaching time. Nursing Research. 33: 147-151.

Rossi, A. Gender and parenthood. In Gender and the Life Course, ed. A. Rossi, Hawthorne N.Y.: Aldine. 1985.

Roter, Debra. 1987. An exploration of health education's responsibility for a partnership model of client-provider relations. Patient Education and Counselling. 9: 25-31.

Stone, Robyn, Gail Lee Cafferata and Judith Sangl. 1987. Caregivers of the frail elderly: A national profile. The Gerontologist. 27(5): 617-626.

Sutcliffe, Caroline and Stuart Larner. 1988. Counselling carers of the elderly at home: A preliminary study. British Journal of Clinical Psychology. 27: 177-178.

Toseland, Ronald W., Charles M. Rossiter and Mark S. Labrecque. 1989. The effectiveness of peer-led and professionally-led groups to support family caregivers. The Gerontologist. 29(4): 465-471.

Toseland, Ronald W. and Charles M. Rossiter. 1989. Group interventions to support family caregivers: A review and analysis. The Gerontologist. 29(4): 438-448.

Wong, J. and S. Wong. 1985. A randomized controlled trial of a new approach to preoperative teaching and patient compliance. International Journal of Nursing Studies. 22: 105-115.

Zarit, Steven H., Pamela A. Todd and Judy Zarit. 1986. Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist. 26 (3): 260-266.

Zarit, Steven H., Cheri R. Anthony, and Mary Boutselis. 1987. Interventions with caregivers of dementia patients: Comparison of two approaches. Psychology and Aging. 2 (3): 225-232.

Zarit, Steven H., and Ronald H. Toseland. 1989. Current and future direction in family caregiving research. The Gerontologist. 29 (4): 481-483.