PRIDE IN ALZHEIMER'S CARE: THE DEVELOPMENT OF A TRAINING PROGRAM FOR LONG TERM CAREGIVERS

by

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Dedication

For Mom and Dad.

Abstract

As the number of those with Alzheimer's Disease rises and the associated costs of care escalate. the need for quality caregiver educational programs and materials has become crucial. Caregivers, as adult learners, require and deserve learning materials appropriate for their needs and abilities. For the most part current educational materials have ignored these needs. The purpose of this study was twofold: to determine what content and teaching-learning processes would be most appropriate in educational programs for caregivers of those with Alzheimer's Disease; and to develop an educational program that would take into account adult learning principles and caregiver strengths and abilities.

The study was initiated by a needs assessment to better determine specific caregiver concerns and by an analysis of existing Alzheimer's curricula. The needs assessment took the form of a survey of administrators of long term care facilities in New Brunswick. The results of this assessment substantiated the need for training materials and helped to establish the parameters within which a training curriculum could be created.

The curriculum was targeted at a caregivers working in a long-term care with little direct education about Alzheimer's Disease. The curriculum was designed to be basic, practical, and useful; consists of twelve hours of training to be delivered as four three-hour modules. The curriculum was validated by three knowledgeable educators and was revised on the basis of their recommendations.

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Chapter One

Introduction to the Study

1.1 Introduction

Alzheimer's Disease is a progressive, degenerative brain disease that generally occurs later in life. and that can take from two to twenty years to inevitably result in death. Although initially innocuous and insidious, the disease progresses throughout the brain killing millions of brain cells and leaving victims helpless to care for themselves. First diagnosed in 1907 by Alois Alzheimer while performing a brain autopsy on a 56-year-old woman, Alzheimer's Disease today is the most common form of dementia found in older persons. It is the third most common cause of death, by disease, among the elderly, after cardio-vascular disease and cancer (Khalsa & Smith, 1997).

Based on studies from developed and developing nations, at least 11 million people have been diagnosed with Alzheimer's Disease worldwide. This number includes approximately four million in the United States and 250,000 in Canada (Canadian Journal of Health and Aging, 1994; Grinspoon, 1998; National Institute of Mental Health, 1998).

In much of the literature, the prevalence of Alzheimer's Disease is masked because it is reported under the heading "Alzheimer's Disease and Other Dementia."[1] Data reported by Elliot, Hunter and Hutchison (1996) indicate that roughly two-thirds of

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[1] Because of the tendency to report Alzheimer's Disease in this way, the term "dementia" is frequently used as a short label for all types of mental disorders whatever the cause. In this study, the various terms are often used interchangeably to avoid repetition and awkward sentences. The study, however, focuses on issues related to Alzheimer's Disease. When the work of other authors is cited, the terms used in this study reflect those which appear in the text of the referenced article.

persons diagnosed as suffering from dementia have Alzheimer's Disease (pp. 164 and 170). These same authors also report the following facts:

- In Atlantic Canada, 8.4% of the population 65 years and over have been diagnosed as having some type of dementia (including Alzheimer's Disease) and 6.0% have been diagnosed as having Alzheimer's Disease (pp. 164 and 170).
- In Atlantic Canada, among persons 65 years and over living in community settings, the rate for all dementia is 4.2% and for Alzheimer's Disease is 3.5%; among those living in institutional settings, the rate for all dementia is 59.4% and for Alzheimer's Disease is 45.1%. These rates are somewhat higher than for Canada as a whole (pp. 164 and 170).
- Across Canada, among persons aged 65 to 74 years, the rate for all dementia is 2.4% and for Alzheimer's Disease is 1.0%. These rates increase exponentially with age to 34.5% and 26.0% among persons 85 years and over (pp. 164 and 170).
- In Atlantic Canada, women have higher prevalence rates for all dementia (8.4%) than men (8.2%), as well as for Alzheimer's Disease — 6.7% for women and 5.0% for men (pp. 164 and 170).
- Women diagnosed as having Alzheimer's Disease are more likely than men to be living in an institutional setting (p. 172).
- Among persons aged 65 to 74 years and living in institutional settings, the ratio between those diagnosed as having Alzheimer's Disease and those diagnosed as having a vascular-related dementia is about equal. Among those aged 85 years and over, this ratio has changed radically and is roughly five persons diagnosed as having

Alzheimer's Disease for every one person diagnosed as having a vascular-related dementia (pp. 172 and 174).

- Approximately half of all persons diagnosed as having Alzheimer's Disease are cared for in a health care facility of some kind. Canada as a whole admits a higher proportion to institutional care than other industrialized nations; the Atlantic provinces admit a slightly lower proportion than other regions of Canada (Canadian Journal of Health and Aging, 1994; Elliot, Hunt & Hutchison, 1996)

Given increased life expectancy and other demographic influences, the number of persons with Alzheimer's Disease who are living in long term care institutional settings will increase dramatically. The number is expected to double by the year 2011 (Elliot, Hunt & Hutchison, 1996, p.168).

Although prevalence is a serious concern with Alzheimer's Disease, it is the costs represented by the growing numbers of persons with the disease that are staggering. The Alzheimer Society of Canada (1997), in a survey conducted in 1993, found that the cost of caring for those with Alzheimer's Disease or a related dementia, in an institution or community setting, was estimated to be over $4 billion. This amount does not include the indirect costs of lost wages and sick time associated with caregiver illness as a result of distress. It is clear that an aging population, with an increasing prevalence of Alzheimer's Disease and other dementia in old age, will represent the major health challenge of the twenty-first century (Bowlby, 1993).

Dippel and Hutton (1996) estimate that 40 to 60% of residents in long term care facilities suffer from some form of dementia. Given the trends already mentioned, the authors point out that the number of persons with dementia will continue to rise dramatically, as will the number of persons admitted to long term care. The burden of providing care for the ever-increasing number of persons with Alzheimer's Disease and other dementia, therefore, will fall squarely on those who provide care in long term institutional settings.

Both the philosophy of delivering care to persons with Alzheimer's Disease and other dementia and the practices related to the teaching of adult learners have changed in recent years. Unfortunately, training programs and materials have not kept pace with these changes. The challenge for this study was to determine what constitutes "quality" care for persons with Alzheimer's Disease and to then develop learning materials and teaching methods that would fit the needs of caregivers charged with providing such care in long term care facilities.

1.2 Purpose of the Study

The purpose of this study was two-fold: to determine what content and teaching-learning processes would be most appropriate in programs designed to train caregivers who provide care for persons with Alzheimer's Disease in long term care facilities; and to develop a training program that would take into account sound adult learning principles, thereby building on unique caregiver strengths and abilities.

1.3 Assumptions

When I began the study, I made two major assumptions. First I assumed there was a plethora of curriculum materials available. In reality, the training materials turned out to be an ad hoc collection that had little, if any, relevance to the principles associated with adult learning. Moreover, materials proved to be difficult to find and agencies which had materials were reluctant to lend them. Because curriculum development is time consuming, labourious, and expensive, and because sources of curricula proved hesitant to release their work for academic study purposes, the curriculum development activities became more problematic than was initially expected.

The second assumption was that regardless of location or type of care facility, all caregivers would be receiving training in how to care for persons with Alzheimer's Disease and related dementia. The reality turned out to be very different. Caregiver training depended on a large number of variables including the type of facility, the care setting, and local and other government regulations, particularly those related to the necessary qualifications of caregivers. The developed curriculum is therefore both basic and generic in nature and can be adapted for use with different types of caregivers and in a variety of institutional settings.

1.4 Background of the Study

This study is qualitative in nature and relies on curriculum mapping techniques (Tennessee Professional Development Website, 2000) and the curriculum materials analysis system proposed by Morrissett, Stevens and Woodley (1969). Curriculum mapping is a procedure for collecting data about existing curricula which allows an educator to analyse trends in content, objectives, and teaching strategies; accumulate data from different sources about existing needs within the context in which the training is to be delivered; make decisions related to the design of new materials; and edit, review, validate and assess developed materials with confidence and in context (Morrissett, Stevens & Woodley, 1969; Tennessee Professional Development Website, 2000).

The research process was an emergent one with data collection in field contexts parallelling the analysis of existing curricula and the design of new materials. The length of the written study grew alarmingly. As a result, decisions had to be made about what information was essential for inclusion in this document and what could be abbreviated and presented in appendices. Since my primary objective was to develop a useable curriculum for a viable training program, my supervisor and I decided we would emphasize the developed curriculum and its validation rather than the data gathered about needs within the field. To help the reader understand the research process I engaged in, I have provided, in this section, a brief history of the entire project.

When I began this project in 1996, I was living in New Brunswick and attending the University of New Brunswick full-time. My first point of contact was the Alzheimer Society of New Brunswick, a branch of the Alzheimer Society of Canada (referred to hereafter as the "Alzheimer Society"). They offered me the use of their library and provided many helpful ideas.

Early on, I also contacted the Kingston (Ontario) branch of the Alzheimer Society because I had read that they were offering training which might be of interest to me. They were using an already established program, entitled the *Care at Home* series (Alzheimer Society of Canada, 1996). I was informed that they had made modifications to the program to suit their regional needs and that I should contact the national office. I next spoke with Linda LeDuc, in the national office, who was very helpful and informative in suggesting where else I could search for curriculum materials. Although she was not able to lend me the material I desired, she offered to sell me a copy of *Care at Home*. She also suggested that I speak with Carol Bowlby (1993) whose book turned out to be an excellent bibliographic source.

In addition to relying on the reflections and published efforts of others, I decided that I wanted to conduct my own needs assessment to determine the necessity for such training. Accordingly, I contacted Rachel Clair of the New Brunswick Association of Nursing Homes and sought her co-operation. At the time, I had hoped to develop a curriculum that could be translated into French which could be offered to her association if it was a suitable product. We developed a needs assessment questionnaire to be completed by an administrator, translated it into French, and mailed it out to the 62 member facilities of the New Brunswick Association of Nursing Homes. The 100 percent response rate surpassed my expectations. Moreover, the thoughtful replies from those who completed the form provided a clear justification for a caregiver-oriented curriculum and a broad information base from which to carry out further investigations.

A limitation of the study is that this needs assessment activity collected data only from administrators and not from caregivers themselves. This choice was made because I lacked the funds and the time to complete a more extensive needs assessment. Furthermore. I assumed that home administrators would be most knowledgeable about the choices related to variables as duration and timing of training sessions and would be able to report, with reasonable accuracy, the needs of their employees.

By August 1997, I was living in the United States, in the state of Virginia. I continued my search by means of the Eastern Virginia Medical School Library as well as the Alzheimer's Disease and Related Disorders Association (referred to hereafter as the "Alzheimer's Association"). The Hampton Roads Chapter offered me the use of their in-house library resources which included a curriculum resource, entitled *Just for the Summer* (Alzheimer's Disease and Related Disorders Association, 1991).

While volunteering on the Education Committee of this local chapter, I was asked by the national office of the Alzheimer's Association, located in Chicago, to become a corporate trainer for the launch of an educational program for activity personnel. This program was piloted throughout 24 states with approximately 48 trainers.

Through these activities, I became familiar with the national Training and Education Division of the Alzheimer's Association. Through them I was able to access a number of resources that proved valuable to the development of the curriculum. Specifically, this association allowed me access to on-line resources as well as the latest print offerings in their library. I was also privileged to work with their assistant director of training and education, Molly Brault, and their education specialist, Julie Klinger, who were. and continue to be, excellent sources of information and direction.

With their assistance I was able to locate two curricula that had been developed by individual chapters of the Alzheimer's Association. Through local library searches and interlibrary loans, I was also able to locate and borrow two additional curricula. Finally, through a friend who worked at the Hampton Roads Department of Veterans' Affairs (DVA), I was able to borrow a curriculum that was being used by DVA hospitals throughout the United States.

Meanwhile I travelled back to New Brunswick to attend a dementia workshop given by Len Fabiano for caregiving staff in Saint John. I participated in this program to become aware of existing training practices. I was surprised by the success of the program because Fabiano's training style was didactic and theatrical, and not, in my opinion, typical of good adult education practices.

In Virginia I attended in-service training at a nearby Jewish nursing facility, and also conducted inservice training at a variety of care facilities throughout the state. Over the Christmas period, 1998, while in Ontario, I visited six nursing facilities to observe caregiver practices.

Through the Internet, I was able to contact the Rush Presbyterian Alzheimer's Disease Research Center in Chicago which became an invaluable source of information. This Center manages a lending library where I was able to access literature and video materials that I could not obtain elsewhere. With the variety of materials I was able to obtain from the various sources mentioned, I was able to write a review of the literature (Chapter Two) and to outline the new curriculum I was developing.

In 1998, I was hired by the Alzheimer's Association to work on a number of different projects. In the first, I acted as an evaluator of a national training program. This gave me the opportunity to observe state of the art training in dementia care. In the second project, I developed, administered, and reported on the results of a questionnaire sent to administrators of long term care facilities in the United States about education and training in their facilities. In the third project, I developed, facilitated and reported on focus groups for caregivers who work in American long term care facilities. The participants in these focus groups reported on their training needs and preferences.

The data from all these various activities became the integrated background which I brought to bear on mapping eleven different curricula. I wrote an extended report for the Alzheimer's Association (Sweetnam, 1999). When I came to write this study, I found that I had difficulty separating out the various sources of information since all the sources were mutually reinforcing. For this document, therefore, I have prepared a summary of the quantitative data obtained from the New Brunswick survey (Appendix A). The main findings from the Alzheimer's Association projects (Sweetnam, 1999) are used in Chapter Three to support, and where appropriate augment, the findings from the New Brunswick study.

Throughout 1998 and 1999, I conducted the curriculum mapping task and wrote Chapter Three of this document. During the same time period, I developed the new curriculum which was validated late in 1999 by three New Brunswick validators. The curriculum was revised and the results of the validation were written up as Chapter Four.

1.5 Limitations

One limitation has already been described in the previous section. The needs assessment activity gathered data only from administrators and not from caregivers themselves. A second limitation is that the reader may find that the terms used in this document do not always conform to traditional usage in the Canadian and New Brunswick contexts. I found that living in Virginia, far from my academic home at the University of New Brunswick, made it difficult to pursue studies that were exclusively aimed at the training of caregivers in New Brunswick. I expanded the parameters of the study, therefore, to include the training practices I encountered in the United States. I believe that the addition of the insights I gained from my experiences in another jurisdiction has enhanced the curriculum materials I have developed. As a consultant and corporate trainer, I have been involved in the development of a similar curriculum for caregivers for the Alzheimer's Association. Because I have drawn on both Canadian and American experiences, the terms used in the curriculum I have developed may reflect this fact. With the help of my supervisor and the validators, I have tried to keep the terminology and training practices consistent with Canadian usage.

1.6 Definitions

For standardization, the use of terms will accord with the following definitions:

Caregiver: persons who are paid workers in a long term care facility and who care for residents with Alzheimer's Disease. The training has been developed specifically for those who do not have more than one year of professional training in their caregiving functions, but the training could be adapted for other persons, such as nursing staff, administrators, food service personnel and custodians, who work in long term care facilities.

Training: in the field of education, training is defined as the act or process of helping an adult learner develop knowledge and skills related to a specific occupation or occupational task. While the term is commonly used by adult educators in the field of human resource development, it is not as commonly used in the field of nursing.

Dementia: a general term which is used to describe disordered cognitive processes (e.g., impaired reasoning and memory) and personality changes. The cause of the dementia can be organic in nature such as occur in Alzheimer's Disease or vascular diseases (e.g., stroke) or functional (i.e., non-organic) in nature such as occur in other mental disorders such as schizophrenia. In the developed curriculum in this study, the term dementia refers specifically to conditions caused by Alzheimer's Disease. Dementia is a collection of symptoms that indicate cognitive changes that are not part of the normal aging process. A differential diagnosis of the actual cause of dementia symptoms is often difficult and the term Alzheimer's Disease tends to be over-used. In long term care facilities few practical distinctions are made between persons with Alzheimer's Disease and persons with other forms of dementia.

Long term care facilities: will encompass all types of facilities that provide care for persons who are admitted for an indefinite length of time. This designation avoids attempting to categorize facilities in terms of the type of care provided, the type of physical facility, the costs, and the degree of public funding.

Resident: Refers to a person who lives in the long term care facility and who receives care from caregivers.

1.7 Summary and Overview of the Thesis

Coping with the difficulties that Alzheimer's Disease presents to our society is an enormous challenge. This is especially so for those who shoulder the burden of care most directly -- the caregivers. Those who suffer with Alzheimer's Disease have the right to be well cared for, loved and valued, and to enjoy life as much as their impairment will allow. Caregivers are the unique providers who contribute most directly to improving the quality of life for persons with Alzheimer's Disease. Health educators, therefore, have a responsibility to provide meaningful and appropriate educational opportunities for caregivers to ensure that they are both enabled and empowered to provide that care.

Chapter Two of this thesis provides a review of the literature on Alzheimer's Disease, on the contemporary practice of delivering care to persons with the disease, on the target audience for the developed curriculum, and on adult learning principles. Chapter Three describes the curriculum mapping procedure and reviews eleven curricula identified for delivering training and educational programs to persons who work with individuals with Alzheimer's Disease. Chapter Four describes the validation procedure, its results, and the revisions made to the curriculum. Chapter Five presents a conclusion and recommendations for future similar endeavours. The developed curriculum, *Pride in Alzheimer's Care*, is provided as Appendix C.

Chapter Two

Literature Review

2.1 Introduction

The need for caregiver training for those who attend to Alzheimer's Disease residents is ubiquitous and compelling. As the 'boom' generation ages and those already in old age live longer, the proportion of those in long term care environments afflicted with Alzheimer's Disease will increase dramatically (Rogers, 1998). Since the incidence of residents with Alzheimer's Disease in long term care is already between 40 and 60 percent, and the proportion of the general population with the disease is expected to double in the next thirty years, the need for appropriate and quality caregiver training in long term care is urgent (Dippel & Hutton, 1996). The most relevant, contemporary and available literature sources were reviewed. Most sources were obtained through the Alzheimer's Association and the Alzheimer Society. This chapter describes the disease and those who care for individuals who are afflicted by it.

A curriculum to deal with the specific needs of residents with Alzheimer's Disease in long term care environments should include expertise in two knowledge bases:

1. Alzheimer's Disease and how it affects those who have it; and
2. the contemporary practice of care.

The process of writing such a curriculum requires that the writer have expertise in three knowledge bases:

1. the target audience for the developed curriculum -- caregivers and their characteristics;
2. the types and adequacy of current learning material; and
3. adult learning principles.

Although these two bodies of knowledge could be classified as separate entities, in the process of using them to develop a curriculum, they become intertwined and complementary. This ultimately leads to an educational product that is much more than the sum of its individual parts.

The remainder of this chapter reviews the literature on the five areas identified above. Chapter Three reviews existing curricula designed to train caregivers in long term care facilities.

2.2 Alzheimer's Disease and Its Effects.

Alzheimer's Disease is a disorder that is determined by definitive changes in brain structures. The exact causes of these changes have not yet been positively determined, but it is known that they are derived from a number of sources. Alzheimer's Disease is not a normal part of aging; rather it is part of a group of diseases or dementia characterized by decline in general intellectual function. In Alzheimer's Disease, decline is irreversible, degenerative and ultimately fatal.

The definitive abnormal brain structures in Alzheimer's Disease are called plaques and tangles. Plaques are deposits outside neurons (brain cells) in brain tissue. They are made from parts of a protein called beta amyloid. Tangles are paired filaments that have become twisted and tangled inside neurons. Generally, the greater the number of tangles in specific parts of the brain, the greater the degree of cognitive impairment. Most of the medical community adheres to the belief that none of these brain changes can be diagnosed definitively without a brain autopsy (Grinspoon, 1998). Others assert that "a clinical diagnosis of Alzheimer's Disease is possible through careful history taking with a reliable informant and a minimum number of laboratory tests "(Gauthier, Panisset, Nalbantoglu, & Poirier, 1997, p.1047).

A clinical diagnosis is based on a number of tests, both physical and neurological. Assessment guidelines, such as those suggested by the Canadian Medical Association (Gauthier et al., 1997), are used to help determine the diagnosis. Guidelines vary from province to province and country to country, and are often not rigorously adhered to by general practitioners.

The following laboratory tests are recommended when Alzheimer's Disease is suspected: a complete blood count, serum electrolytes, urine analysis, calcium and glucose levels, and thyroid function studies (Mace & Rabins, 1991). A complete medical history of the person should be given by a reliable source; this may or may not be the person suspected of having Alzheimer's Disease. A neurological examination should also be given and includes a cognitive test, such as the Cognitive Capacity Screening Examination, or clinical observations, and a psychiatric screening to test for depression or other treatable conditions (Bowlby, 1993; Dippel & Hutton, 1996; Gauthier et al., 1997).

The diagnosis of Alzheimer's Disease was formerly one of exclusion -- if it is not anything else, it must be Alzheimer's. Since 1998, however, the Canadian Consensus Conference on Dementia (Gauthier et al., 1997), the American Association for Geriatric Psychiatry, the Alzheimer's Association and the American Geriatric Society (Small et al., 1997) have all determined that Alzheimer's Disease diagnosis is essentially a clinical decision based on a standard battery of tests which rule out other causes and show a pattern of decline indicative of Alzheimer's Disease. Upon the discretion of the physician, any number of additional tests can be considered.

The result of this methodology is that Alzheimer's Disease has become the most over-diagnosed and misdiagnosed disorder of mental function in old age (National Institute of Mental Health, 1994). Indeed, there are more than 70 conditions or disorders, some of which are reversible, that closely resemble Alzheimer's Disease. These include drug addiction, alcoholism, brain tumors, head trauma and nutritional deficiencies (Bowlby, 1993; Dippel & Hutton, 1996; Mace & Rabins, 1991).

The difficulty with diagnosing Alzheimer's Disease stems not only from the lack of a definitive laboratory test, but also from the variability of its symptoms. The disease symptoms are enormously capricious with cognitive abilities and skills present one day, and not the next. Moreover, the tasks of daily living which include washing, bathing, dressing, toileting and eating can be performed one day, forgotten the next, and then remembered again. As Mace and Rabins (1991) have pointed out, and Fazio, Seman and Stansell (1999) have emphasized, the only consistency with Alzheimer's Disease symptomology is its inconsistency. Despite the variability, people with Alzheimer's

Disease, as Gauthier et al. (1997) have suggested, deteriorate through *relatively* predictable stages.

Alzheimer's Disease can last from two to twenty years, with the average duration from time of diagnosis to death being approximately seven to eight years (Bowlby, 1993; Gruetzner, 1992; Rogers, 1998). In order to more accurately diagnosis, treat, and determine the type of dementia, Alzheimer's Disease has been isolated from many others by categorizing its symptoms into stages.

Two of the most notable staging tools that have been developed are the four stage scale of Volicer, Fabiszewski, Rheaune and Lach (1988) and the seven stage Global Deterioration Scale of Reisberg (1983). For the purposes of cognitive testing throughout the disease progression and pharmacological intervention, the Reisberg scale is most widely used. The Alzheimer's Association commonly refers to a simplified three stage model (Alzheimer's Disease and Related Disorders Association, 1996). The Alzheimer Society (see http://www.alzheimer.ca/alz/content/index-disease-eng.htm) uses both a three stage model and Reisberg's seven stage model depending on the audience. In all cases, the stages indicate behaviours and inabilities that reflect the severity of the disease. The three stage model is described here because it seems most appropriate to the educational purpose of the study.

First Stage. The first or early stage of the disease is often overlooked or misdiagnosed since the symptoms are often wrongly associated with normal aging. The most noticeable characteristic that may occur early in the disease progression is the loss of short-term memory (Khalsa & Stauth, 1997; Mace & Rabins, 1991). Events of the distant past remain intact; however events that occurred in the more recent past, especially if they have little emotional impact on the person, are forgotten. This problem starts innocently enough and progresses to a noticeable state where tasks of daily living are either forgotten or repeated several times. People in Stage I who have Alzheimer's Disease are usually also impaired to some degree by aphasia, a general term that indicates a condition typified by difficulty with language (Bowlby, 1993). This can be manifest in writing (agraphia), in which patients forget how to form letters; or in reading and understanding, in which little of what has been read or said can be retained, especially if they try to explain it. It may also affect speaking, in that patients forget their train of thought, and even word finding, in which they forget the name of an object, incorrectly replace its name with another, or use a description of its function.

People in Stage I may become lost in familiar places or have difficulties with time. Behaviourally, they may be depressed, have mood swings, and/or personality changes. They may either become lethargic and lack motivation or become restless, suspicious, and aggressive (World Health Organization, 1994).

Second Stage. By the second stage many of the above mentioned behaviours may worsen and other symptoms will appear; but occasionally, the person will be lucid and appear normal. However, most need help with activities of daily living -- washing, bathing, dressing and toileting (Mace & Rabins, 1991). At this point, wandering, disruptions to the sleep/wake cycle, sexual disinhibition, bladder and bowel incontinence, and more severe aggressiveness often occur as well (Gruetzner, 1992). It is the progression in frequency and severity of these symptoms that make care at home difficult and admission to a long term facility an inevitability for most people (Mace & Rabins, 1991; Rogers, 1998).

Third Stage. The third stage is characterized by further deterioration or exacerbation of the above mentioned symptoms. At this point, physical deterioration becomes manifest as well. There may be difficulties with gait and balance. The person may have difficulty eating or swallowing and may be confined to a wheelchair or bed. Meaningful communication may not be possible. Speech becomes limited to oft repeated greetings or colloquialisms. Repetitious behaviours or vocalizations may occur. The person is likely to become bladder and bowel incontinent, and will usually not recognize spouses, children, relatives or friends (Mace & Rabins, 1991; Rogers, 1998; World Health Organization, 1994).

People who are in the final stage of Alzheimer's Disease are immobile, bed ridden, unable to communicate orally, and may need to be fed. When the patient is no longer able to smile, respond with "yes" or "no" or react to pain, the final stage of the disease is near. Death is usually a result of pneumonia or other infections (Khalsa & Stauth, 1997).

Designating the stage of the disease for an individual is often difficult. The individual may show symptoms of one stage but be in another. Stages may overlap. Assigning a stage to a person with Alzheimer's Disease may be of little consequence and can actually aid in depersonalizing the individual (Fazio, Seman & Stansell, 1999; Seman & Stansell, 1995). Furthermore, the disease is progressive in the sense that losses are cumulative and so gradual that it is difficult and sometimes erroneous to place an individual in one particular stage or another. Rather than limiting a person with Alzheimer's Disease to what is indicated by their stage, it is more appropriate to access the abilities they still have and enjoy doing (Bell & Troxel, 1997).

2.3 Contemporary Caregiving

Two schools of thought exist today concerning the most appropriate culture of care for those with Alzheimer's Disease and related dementia. The most recently developed school of thought advocates a 'psycho-social' culture of care that is based on a positive relationship between the caregiver and the person with the disease; and on personalized care practices and routines based on the needs and abilities of the individual with the disease (Kitwood, 1997). The older, more established school of thought is a so-called 'medical or custodial model' in which care is based on established schedules, treatments and job descriptions (Johnson, 1994; Kitwood,1997).

Psycho-Social Model. The 'psycho-social' model of care has several advocates who share a similar philosophy toward care. The Eden Alternative created by Dr. William Thomas (Tavormina, 1999) recognizes that those who live in long term care facilities suffer from loneliness, helplessness, and boredom, and that these emotions cause needless suffering. Thomas believes in creating environments in which the human spirit is nurtured, care is compassionate, and the improvement of the resident's quality of life is an on-going process. Fabiano (1998) and Fazio, Seman and Stansell (1999) have spoken about the need to abandon care that is rehabilitation- based and move toward a supportive therapy where the maintenance of personal self-worth is fostered.

This psycho-social model of care has several components and an inter-relational dynamic (Kitwood, 1997). This new culture of care should involve positive interpersonal relationships between caregivers and those they care for. Furthermore, care plans should be created with individual interests, needs, and desires of the person with dementia in mind. The kind of care delivered should concentrate on the maintenance of abilities rather than focussing on disabilities. Care should be compassionate and nurturing, and the self-understanding of caregivers is used as a resource for the delivery of quality care (Dippel & Hutton, 1996; Fabiano, 1998; Gwyther, 1985). A psycho-social model of care does not focus on highly technical medical or pharmacological interventions alone, but on combining the high tech approach with understanding and respect. This new culture of care requires a paradigm shift in one's approach to care (Kitwood, 1997).

Medical Model. The advocates for the traditional or medical model of care represent a culture within which Alzheimer's Disease is thought of as a degenerative disease that eventually destroys personality and identity. In this approach, the pathology of the disease and how to treat it are more important issues than the patient's individual needs (Kitwood, 1997). Hence, in the medical model of care the personhood of those who have Alzheimer's Disease often becomes lost in the science and practice of medicine. Because there is no cure or rehabilitation for the disease, good quality care consists of competently addressing physical care through providing for basic needs rather than addressing the complexity of the person (Kitwood, 1997).

LeDuc (1993) and Johnson (1994) are even more explicit in their descriptions of a medical or custodial model of care. They speak of care that is organized by schedules in which residents become variables that must be fitted into the agenda. This produces a situation in which the person with the disease, despite disabilities and formidable cognitive limitations, must conform to a pre-established system. The medical model fosters an attitude of care which makes scheduling more important than the resident and employs caregivers who are not expected to think independently because the schedule informs them what to do next.

In the medical model, the physical demands on the caregiver are many, but the mental challenges are few, except for the enormous stress that they endure. Caregivers are tasked with an unrealistic number of assignments and heavy physical work. Caregivers such as these have little control, need few skills and are little inspired to improve any quality of life save their own (Kitwood, 1997).

The shift from a medical model to a psycho-social model can result in resistance to change. The medical model represents many years of established care routines, budgets, and standard resident-to-staff ratios that are difficult to displace. In reality, any organizational change is difficult, especially when the advocated changes represent non-alignment with the current trends of standardization and cost reduction (Kitwood, 1997). Seman and Stansell (1995) have suggested that we have to be careful to not keep doing what we have always done just because it has always been done that way. They advise that following established routines can become barriers rather than effective mechanisms in the provision of quality care.

However, as 'baby boomers' age, attitudes toward aging will change with them. Corporations whose business is long term care cannot afford to ignore the values of this large, well-educated, well-informed, and influential generation (Popcorn, 1992). Families who are placing loved ones in long term care are looking for much more from caregivers than a basic fulfillment of biological needs. Kitwood suggests that caregivers who have only good basic feeding and toileting skills can no longer be considered as able to deliver quality care. Families search for excellent care when they are attempting to place loved ones. Administrators who ignore such requirements, do so at their peril (Kitwood, 1997).

Kitwood (1997), in reference to changing the culture of care, has referred to the paradigm shift as a moral imperative; and Tavormina (1999) has spoken of the philosophy of the Eden Alternative as "doing the right thing." The philosophy of providing care in a dementia setting has evolved dramatically in recent years; however, the basic education of caregivers has not. In recent years, money for education and training has traditionally been a budget area which is cut in hard economic times. Educators of caregivers have struggled to direct dwindling dollars toward training related to the new culture of care.

2.4 The Burden of Cargiving

Caregivers, regardless of the model of care, must cope with certain behaviours from residents that are very challenging. Such behaviours often become stressors and include: repeated questioning, catastrophic reactions (those which are more dramatic than would normally be expected), angry reactions both to offers of assistance or to not being offered assistance (Mace & Rabins, 1991); suspiciousness, accusations, hallucinations. inappropriate vocalizations, and restlessness (Bowlby, 1993). Sometimes the resident will shadow the caregiver by closely watching or following him or her, or may refuse to bathe, groom or change clothes (Greutzner, 1992). Often patients may wander, refuse to eat, rummage, hoard, swear, make inappropriate sexual advances to caregivers or other patients, or may be bowel and bladder incontinent (Greutzner, 1992; Gwyther, 1985; Mace & Rabins, 1991). Other stressors include unreasonable demands by the employer, the resident or the family.

At times, the best efforts of caregivers can unintentionally make the disabilities of their patients worse. For example, adherence to an inappropriate schedule may expect too much of the resident and cause frustration and undue hardship. On the other hand, expecting too little of residents or doing too much for them, robs them of their remaining abilities and self-respect. Caregivers may speak too softly; or the resident may not have a caregiver who can speak their first language. Such conditions adversely affect the ability of the resident to cope with their own disease and with the environment. Caregivers need to be aware of how their own expectations, culture, beliefs, and lifestyle differ from that of the residents so that the caregiver can adapt. Someone afflicted with Alzheimer's Disease cannot make such adaptations (Bell & Troxel, 1997; Bowlby 1993; Fazio, Seman & Stansell, 1999; Kitwood, 1997; Seman & Stansell, 1995).

2.5 The Target Audience for Training

The people who are most directly involved in the care of those with Alzheimer's Disease in a long term care facility are caregivers. In this study , the term "caregiver" is used to describe persons who work with individual residents to provide for personal and basic daily living needs such as feeding, dressing, toileting and personal grooming. Most such persons have less than 12 months, or no preparatory training. Most receive initial on-the-job training from their employer; some receive further training (e.g, first aid. CPR) related to specific knowledge and skills through government-employer co-operative programs. In order to create a training curriculum for caregivers, it is important to understand the characteristics of both the caregiver population, and the environment in which they work.

Caregivers are in a position of being able to directly affect the quality of life that persons with dementia enjoy. They provide the majority of care and have more contact with residents than anyone else, including the family. In fact, it has been established that caregivers in the long term care environment provide the vast majority of nursing home care in general (Austrom,1996).

The most important element in a good special care program is the staff. The way caregivers' jobs are described would lead some to think otherwise. Caregiver work is unrealistic in terms of the demands made on the time and abilities of the worker. Caregiving work is also underestimated in terms of the physical and mental demands on the workers. Furthermore, caregivers are poorly paid, are offered little career advancement, and receive little recognition (Austrom,1996; Foner, 1994; Kane &

Caplan, 1990; Szwabo & Stein, 1993). Some of the characteristics which affect training, as well as the quality of caregiving include: cultural differences, family income, academic history, gender, age and stress level.

2.5.1 Cultural differences

Caregivers who work in long term care represent a segment of the working population with particular characteristics and inherent needs as adult learners. In large urban areas, the majority of caregivers are young and generally represent ethnic and racial minorities, such as African/Canadian, Hispanic, Oriental, or whatever dominant minority is represented in that area (Tellis-Nayak & Tellis-Nayak, 1989; Foner, 1994). In contrast, caregivers from rural areas are usually white and older. Universally, as Patterson (1990) has pointed out, caregivers tend to be women.

The issue of ethnicity and cultural differences have implications for caregiver training that have not been well studied. Caregivers may be new immigrants from cultures far different than those of their residents, with different values and different understandings of families, aging, behaviour, and dementia. They may have little understanding of a disease that is not recognized in the country of their birth or they may have little comprehension of, and poor attitudes toward, families who place loved ones in institutions (Beck, Ortigara, Mercer & Shue, 1999).

These individuals may not be proficient in speaking, understanding or reading the language used in training activities. Often such learners are astute at covering up their limitations, so facilitators must carefully observe and thoughtfully prepare training that capitalizes on the caregivers strengths and minimizes their difficulties (Tellis-Nayak & Tellis-Nayak, 1989).

Educators should also take into account that caregivers are caring for persons of a different generation; and this, in itself, may pose another cultural difference which can affect training. For example, a non-Caucasian 21-year-old woman may have difficulty caring for an 80-year-old man from a small New Brunswick town, whose residual racist attitudes were acceptable 50 years ago. To this end, Beck et al. (1999) and Mercer, Heacock and Beck (1993) have recommended that educators be sensitive not only to the cultural milieu of residents and caregivers, but also to their social milieu.

2.5.2 Family income.

According to Mercer, Heacock and Beck (1993) and Foner (1994), caregivers come from lower-income families. Single parenthood, poor health, child support concerns, household arrangements, transportation costs, and money management all have implications for such caregivers. Educators of caregivers must recognize these characteristics in the adult learners in their programs before they can begin to recognize the impact such differences have in both training and the workplace. Low income, single mothers with children, when employed as caregivers, face tremendous pressures, and may have had to overcome great difficulties in their lives. Learners who have come from difficult or abusive backgrounds may have special learning needs, and may need extensive support in order to learn (MacKeracher, 1996). They may need special support in connecting new material to its application in their workplace.

2.5.3 Academic history

In terms of academic background, the majority of caregivers have completed (or nearly so) high school, but very few have any further education (Mercer, Heacock & Beck. 1993). Beck et al. (1999) have reported that caregivers are often non-traditional learners who sometimes possess limited reading skills. Caregivers, therefore, need learning materials adapted to a high school reading level and learning activities that avoid excessive use of lecture-based instruction and content-based assessments. Facilitators need to adjust their methods to take advantage of the resourcefulness, past experience, and existing knowledge of their learners (MacKeracher, 1996).

2.5.4 Gender and age

Since the vast majority of caregivers are women, special attention needs to be afforded to their learning needs, learning styles and learning strengths. Women in training programs may need special attention or require specific facilitation skills in order to find their voice, and to expand their ways of learning or knowing (Belenky, Clinchy, Goldberger & Tarule, 1986). Women tend to learn better in an environment in which they can establish a connection with other learners. Often learning is more successful when life stories or narratives are shared and validated amongst others. The process of learning best suited to many women may be a collective or collaborative process. For these women, future learning needs to be grounded in past experiences. Collaborative learning is more likely to occur where small groups of individuals learn to trust each other and the facilitator (MacKeracher, 1996).

Caregivers can range in age from the early twenties to the late sixties. This range poses additional challenges to facilitators. No studies were found which examine the differences between the training needs of older women caregivers and their younger counterparts. Careful consideration must be given so that teaching methods that are appropriate for a younger population do not supersede the needs of the older learners, or vice versa.

2.5.5 Stress

Stress reduction is an area of great concern in learning how to cope with caring for someone with Alzheimer's Disease (Greutzner, 1992; Kitwood, 1997; Mace & Rabins, 1991). Those who work in long term care may suffer burnout due to being overburdened with chronic work-related stress. Stress adversely affects the quality of care delivered by caregivers. Those who suffer from stress tend to call in sick, come in late, or quit (Heine, 1986). However, training can provide opportunities to interact with peers, thereby enhancing career development, providing time for reflection and thought, and counteracting the negative aspects of chronic stress (Hamdy, Turnbull, Norman & Lancaster, 1990).

Experts in the field point out that, as the number of those with dementia increases, the need for caregiver training will also dramatically increase (Beck et al., 1999; Whall et al., 1999). The challenge is to provide meaningful training through a curriculum that addresses the needs and strengths of these special learners.

2.6 Training Programs for Caregivers

To date, those who work with residents with Alzheimer's Disease receive little training (Kitwood, 1997). Those who do attend formal training programs receive training that concentrates on the technical aspects of care, training consistent with the medical model of care (Dippel & Hutton, 1996). Hays and Dowling-Williams (1997) have argued that professional schools for caregivers do not provide specialized training in caring for those with Alzheimer's Disease and other forms of dementia, or for those who are over 65 years of age. The authors added that caregivers receive no training in providing support for the families of those with Alzheimer's Disease nor in how to deal with a family's potentially unrealistic expectations. They also do not receive training in stress relief for themselves, for those with Alzheiemer's Disease, or for their families. Finally, they are little prepared by their training to deal with either the aggressive behaviour of some patients or the combined effects of their physical and mental deterioration.

As Schiff (1994) has pointed out, people with Alzheimer's Disease and related dementia need specific and special kinds of care that support their self-esteem and dignity. Such care calls for special training. As Kitwood (1997) has lamented, the well-being and training of caregivers have been sadly neglected. Among care workers who responded to a study of care practices in Ontario's homes for the aged, about 55 per cent received insufficient training. This particular deficiency was one of the three most serious concerns for staff members (Flett Consulting Group, 1992).

LeDuc (1993) has clarified the lack of training in Canada by explaining that, although materials are available, facilities often do not make use of such materials and few are available in French. She cited such problems as the cost of materials, knowledge of the materials' existence, poor marketing of materials, poor knowledge of outside resources, lack of professional expertise to facilitate training, inappropriateness of materials for use in leaderless groups, lack of self-directed materials, lack of funding, and the lack of staff to replace those who are attending training. Mace (1996) has commented that dementia training materials have only existed for 15 years, that dementia training is immensely challenging, and that there is a long way to go in providing training in which learning has a practical application and is evaluated in terms of the actual delivery of care. Dippel and Hutton (1996) have claimed that the gap in training is not always because of the lack of materials, but because existing materials are not immediately applicable, and this for a variety of reasons.

In Ontario, administrators who responded to a study directed at special care units for dementia residents (Flett Consulting Group, 1992) reported that their most serious concern was the need for staff to be absent from work to attend training sessions (87.8%). Others reported that staff were too busy on the floor to participate (78.3%), that there were no funds for staff training (67.9%), and that the expertise available to lead sessions in their area was not available (61.1%).

Administrators often believed that money for training caregivers is money poorly spent. They based this belief on the fact that the high turnover rate -- varying from 40-70% (Austrom, 1996) to 70-100% (Mercer, Heacock & Beck, 1993) -- among caregivers in long term care makes the allocation of budget money to staff training a waste. Such short-sightedness, however, fails to recognize that training may lower stress for caregivers, increase morale, result in fewer sick days, and lower the rates of absenteeism and turnover. The single most important element in a good special care program is the staff (Kaplan, 1998). Kitwood (1997) has affirmed that those who ignore the well-being of caregivers do so at their peril, as caregiver ignorance will become manifest sooner or later in the care provided to long term dementia residents.

Studies that report on the outcome of training for caregivers suggest positive results. Teri, Baer, Orr, and Reifler (1991) reported that, with a two-day training program, 86% of staff who were trained indicated that the training provided them with new skills in working with those with dementia. As well, 87% were making daily use of the reference manual that was used to train them. Aronstein, Olsen and Schulman (1996) studied the training of caregivers in the behavioural management of residents with Alzheimer's Disease and reported that the project was very successful.

Another study (Maas, Buckwalter, Swanson & Mobily, 1994) examined the effects of educational programming and found that a positive correlation existed between training and job satisfaction. This study suggested that education for those who care for people with Alzheimer's Disease is also related with lower rates of absenteeism.

A comprehensive search was completed for studies conducted in North America and England that specifically evaluated resulting changes in the delivery of care. In the areas searched, no recent studies were found which specifically evaluated the quality of care and the quality of life for residents following caregiver training. An article by Beck et al. (1999) reviewed six studies conducted in Sweden that specifically evaluated the effects of training caregivers in terms of improvement to the quality of life of residents. These studies indicated a positive correlation between the training that caregivers received and measurable improvements in the care delivered to those with Alzheimer's Disease and related dementia.

2.7 Adult Learning Principles

With current caregiving philosophy in mind, Alzheimer's Disease content in hand, and the needs of the caregiver at heart, the next step in the curriculum writing process was to tie the three bases of knowledge to sound adult learning principles. The literature available in the field of adult learning is very extensive; only nine principles, those most directly applicable to educating caregivers in long term care facilities, have been selected from among the many available. (Apps, 1991; Mace, 1996; MacKeracher, 1996; Zemke & Zemke, 1988).

These principles are described in greater detail in the sub-sections that follow:

1. Learning is learner centred.
2. Learning is an on-going process.
3. Learning is cumulative.
4. Learning is goal-oriented.
5. Individuals learn in different ways.
6. Emotions shape the learning experience.

7. Reflection is important in learning.
8. Learning is based on learner activity.
9. Women and men learn differently.

2.7.1 Learning is learner centred

The psycho-social model of care is centred on the needs, interests and desires of the person receiving the care. Just as caregivers need to learn that care should be person-centred. the training they participate in should be learner-centred. That is, the needs, desires and abilities of the learners must be the impetus for not only the content of the training, but also for the methodology. The training must contain information that caregivers will use, either in a skill or as a tool to aid comprehension. If the information is not relevant to their experience, it will neither be valued nor retained (Gilley & Boughton, 1996).

2.7.2 Learning is an on-going process.

Care that is person-centred is an on-going process. The caregiver must continuously learn about the changing needs of those receiving the care. The programs through which the related training is delivered must emphasize that the learning associated with the psycho-social model of care is also on-going.

Just as a person cannot become known to someone in an eight hour shift, neither can the skills or the knowledge a caregiver needs to be proficient in their profession be learned in a one-time effort. If they wish to make their job easier and their delivery of care better, caregivers must continue to learn new skills, new ways of coping, and new characteristics about their residents. Good caregivers need to understand that learning is a process, not a task to be started and completed (MacKeracher, 1996). Caregivers will continue to learn, deliberately or not, throughout their working lives.

2.7.3 Learning is cumulative

Consistent with the principle that learning is an ongoing process is the notion that learning is cumulative. Caregivers bring a variety of valuable life experiences and skills to the caregiving profession. Zemke and Zemke (1988), Hekelman, Segall and Wykle (1989) and Mace (1996) have advised that curriculum should build on existing skills and strengths. Theory about experiential learning tells us that all learners come to a learning situation with some relevant background; they rarely enter a learning program with a blank slate (Kolb, 1993). Each learning event is built on previous knowledge and contributes to the next learning event. Good facilitation starts learners from their pre-existing knowledge base so that new learning rests securely and squarely on what the learner already knows (Apps, 1991).

2.7.4 Learning is goal-oriented

Learning for caregivers should be goal oriented (MacKeracher, 1996; Zemke & Zemke, 1988). Caregivers will want to learn knowledge and skills that make their jobs easier to perform, that make sense, and that offer personal benefits to them. As Svinicki and Dixon (1987) have pointed out, learning is more meaningful when it is immediately applicable in related experiences. Motivation to learn is increased when the knowledge and skills to be learned are clearly perceived as having immediate value and can be successfully applied in real life settings early in training.

Traditional didactic, theoretical approaches to training may not be applicable to caregivers' needs. Learners, according to Zemke and Zemke (1988) and MacKeracher (1996), learn better when they can incorporate their new knowledge and skills through concrete practices. Turner (1996) has pointed out that only 17% of learners in workplace training programs are 'information learners' -- that is, people who read texts, listen to lectures, and learn through the traditional school experiences. Workplace training, therefore, should incorporate many opportunities to put knowledge and skills into practical use in concrete situations.

2.7.5 Individuals learn in different ways

How adults take in information, select relevant information, and incorporate new material into existing knowledge is called a learning style (MacKeracher, 1996). Each individual has a preferred style or way of learning that may or may not be consistent with the styles of the facilitator or of other learners in their group.

Because individuals learn in different ways, it is necessary to incorporate a number of different learning strategies and methods into any training program to ensure that all types of learners have an opportunity to learn, in their preferred style. Grant, Kane, Potthoff and Ryden (1996) and Hekelman, Segall and Wykle (1989) have found that a diversity of training techniques develops more effective training programs. The training methods include discussion, role playing, guided imagery, brain-storming, lecture, and journal writing.

Beck et al. (1999) have suggested that most caregivers are non-traditional learners who learn better in alternative classroom arrangements. The discussion of caregiver characteristics points out that they may not be high academic achievers. Some caregivers have not succeeded in the traditional academic sense, some may have trouble with reading skills, and some may read, write and speak in a language other than English or French. Learners with such characteristics need special consideration in the design of learning programs.

2.7.6 Emotions shape the learning experience

Adult learning is a risky business. Learners need a safe place to discover, practice and discuss new learning (MacKeracher, 1996). Learners will not learn in an environment in which they are fearful of reprisal for voiced opinions, they feel that their efforts will be mocked, or they fear they will 'fail' in learning tasks. Learning can be uncomfortable when it requires the use of new and untested knowledge or skills. Often learning requires unlearning, in which one set of ideas or behaviours must be replaced with another. Learners may need considerable support to overcome their fear of moving from the known to the unknown and to deal with any fears related to potential failure (Beatty & Wolf, 1996; Gilley & Boughton, 1996; Zemke & Zemke, 1988).

Given the caregiver profile described earlier in this chapter, facilitators must diligently work to create a learning environment that is conducive to learning. In this environment, learners must be assured that their self-respect can be maintained, their existing knowledge will be validated, and their efforts will be applauded. Learners must feel free to interact, to be accepted, and to trust the other members of the group and the facilitator (Gilley & Boughton, 1996).

2.7.7 Reflection is important in learning

Kitwood (1997) and the Flett Consulting Group (1992) have indicated that the teaching methods incorporated in caregiver training should include self-reflection exercises. They maintained that self-reflection promotes keen observation of one's own behaviour. MacKeracher (1996) has suggested that reflection offers an opportunity to figure out what worked, what didn't, and why. Close observation of their own behaviour should help caregivers become more aware of their strengths and their own training needs.

Boyd and Fales (1983) have maintained that the key to applying learning, changing behaviour and learning from experience, lies in reflection. This process calls for an examination of what is learned in relation to one's self and one's existing behaviour. The authors claimed that the use of self-reflection distinguishes between those who participate in training, yet continue to repeat old behaviours, and those who participate and whose behaviour changes.

Thatcher (1990) has advocated debriefing, a process which adds a social aspect to self-reflection as a means to make learning more meaningful. He suggested that the critical point in learning is the change, from initial behaviours to new or revised behaviours, which occurs after a learning activity. Since such change rarely takes place in isolation, Thatcher suggested that a post-learning discussion with others about what has occurred fundamentally adds to the learning experience.

2.7.8 Learning is based on learner activity

Actively involving participants in learning events is crucial to its success (Zemke & Zemke, 1988). Adults need to have some control over what, and how, learning occurs. Whall et al. (1999) and Knowles (1980) have found that whenever learners are included in the planning or modification of the learning process, they are more interested and cooperative. Active learning involves discussion, role playing, and skill practise. The opposite of active learning is more passive and includes listening (without discussion), reading, and observing others without trying things out for oneself.

2.7.9 Women and men learn differently

Learning principles that apply to women are important in this discussion since caregivers are predominantly women. How women learn can be fundamentally different than men. MacKeracher (1996) has suggested that women base their learning on their own experiences, on making connections with other learners, and on using the collective perspective of others to validate their own learning. Training, then, should entail using techniques to foster rapport, to provide opportunities to search for and share knowledge based on personal experiences, and to encourage small group activities to foster group cohesion and trust.

2.8 Facilitating Principles

From a facilitator's point of view, having an awareness that the learners will probably learn in a different manner than themselves is crucial to the success of the caregiver learning process. Without careful introspection concerning how to teach the learners in question, facilitators may unconsciously slip into training styles and methods through which they themselves learn best. Facilitators' self-awareness in terms of their own strengths and limitations, and their beliefs and misconceptions, are critical to training with the learners' goals in mind. This notion is clearly illustrated by Tellis-Nayak and Tellis-Nayak (1989) who advocated two basic facilitating principles: use a variety of teaching practices and do no harm.

2.8.1 Variety of delivery formats

Grant et al. (1996), as well as Nayak and Tellis-Nayak (1989). have advised that an assortment of training approaches should be used to provide caregiving learning experiences. They suggested that training should include discussions, videos, reading materials, role-playing and training manuals. MacKeracher (1996) added that new information should be presented through a variety of senses and experiences. New information that is repeated through a multiplicity of modalities is more likely to be learned and retained than information that is presented in only one way.

2.8.2 Do no harm

Mace (1996), as well as Nayak and Tellis-Nayak (1989), has suggested that training should not do any harm. This notion is based on the Hippocratic oath that physicians must take in order to practice medicine. As a principle for training adult learners to be caregivers, the phrase has multiple meanings. Training should give caregivers the tools to do their job better -- that is to deliver a better quality of dementia care. Training that 'does no harm' should be training that first and foremost does not harm the resident, and does not put the caregiver in harm's way as care is delivered.

Training should strive to improve the self-esteem and self-worth of the learners, not harm by diminishing esteem or self-worth. It should give the caregiver pride in newly-acknowledged talents and new-found skills in the practice of caregiving.

2.9 Summary

As the review of the current literature makes clear, there is a compelling need to develop better training for caregivers of persons with Alzheimer's Disease. However, long before a conscientious facilitator attempts to train a group of learners in the delivery of a better quality of care, a framework to construct a curriculum needs to be established. This framework should be based on several factors.

First, the framework should be based on a practical, working knowledge of Alzheimer's Disease and how it is manifested in those who reside in long term care facilities. Second, the characteristics of the caregiver must be understood. Those in caregiving work face unique and difficult challenges and possess unsung strengths and unrecognized abilities. Ethical training requires recognition and acceptance of these caregiver characteristics.

Third, the framework must be based on sound adult learning principles. Nine learning principles were selected, from among the many expounded in the literature, as the most salient to caregiver training. Such principles are often ignored in curriculum development. Few studies make reference to adult learners and fewer curricula are actually based on the art of helping adults learn.

Finally, training caregivers in the care of persons with Alzheimer's Disease within workplace settings is a relatively new concept. To avoid reinventing the wheel, a comprehensive search was conducted to examine the most current efforts in training caregivers. Existing programs were examined to reveal their successes, failures, difficulties and omissions. This review is presented in Chapter Three.

Chapter Three

Curriculum Development

3.1 Introduction

This chapter outlines the approach I used to obtain the information necessary to develop a curriculum for caregivers working with persons with Alzheimer's Disease in long term care facilities. Two major tasks are described. The first task involved gathering data about the needs of the target audience for the training. The second task involved identifying, reviewing and assessing existing curricula on the topic of Alzheimer's Disease and related dementia.

3.2 Needs Assessment

Early in the study, I decided that I needed to gather some data on the needs of the target audience for the training within the New Brunswick context. With the assistance of Rachael Clair, Executive Director of the New Brunswick Association of Nursing Homes, I developed a questionnaire to be mailed to and completed by the administrators of the homes which were members of the association. The questionnaire was translated into French; and the two linguistic versions were mailed to 62 homes, 41 English and 21 French. The return rate was 100%. Gathering data from administrators was an expedient procedure related to lack of funds and time. If time and resources had permitted, data would also have been gathered from caregivers directly.

The data from the questionnaires is shown in Appendix A as frequency counts for each question. The results indicate the following:

- The majority of respondents (90%) believed training about caring for residents with Alzheimer's Disease was needed and that such training was very important (77%).
- The most preferred format (44%) was two to three hour sessions delivered during the day with in-house training preferred.

- The most appropriate total number of hours for such training was deemed to be between six and twelve hours (45%).
- The most appropriate reading level for materials to be used in such a training program would be about grade 11 since the majority of caregivers were reported to have more than grade 10 education.
- Since the majority of caregivers had five or more years of experience, any training program would need to take that experience into account.
- Only 16% wanted training materials in the French language only, while 45% wanted materials in English only and 39% wanted materials in both languages.
- The content desired for such training included:
    - How to work with families (100%)
    - How to work with difficult resident behaviours (100%)
    - How to cope with daily living activities for residents (90%)
    - Knowledge about Alzheimer's Disease (87%)
    - Dealing with the stress of caregiving (80%)
- Open-ended responses to the final question indicated that major concerns among the responding administrators were: improving communications among employees and between employees, residents and family members; enhancing co-operative work activities; and reducing stress and any resulting burn-out among caregivers.

Additional information about caregiver needs came for two projects completed for the Alzheimer's Association (Sweetnam,1999). These projects gathered data through questionnaires and focus groups. Although the resulting data were gathered in a different context and are not considered to be part of this study, the ideas expressed by the participants do not conflict with, indeed tend to reinforce and expand, the ideas gathered in New Brunswick. These ideas include:

- keeping each training session to less than three hours;

- basing evaluation of the training on improvements in the quality of resident life;
- providing certificates and recognizable tokens for successful participants;
- using role plays, case studies, experiential learning activities and videos as the dominant teaching strategies rather than lectures;
- dividing the curriculum into modules with bridging activities leading from one module to the next; and
- providing information about the effect of drugs.

The American caregivers in the Alzheimer's Association project reported that those who do the most hands-on resident care are the least educated and receive the least training to carry out their tasks. They viewed this lack of training as contributing to their frustration over low pay, lack of recognition and stress, and as resulting in high employee turn-over (Sweetnam,1999). The American administrators in the Alzheimer's Association project believed that training would improve the work environment by helping individual staff members to connect with co-workers and to share the burden of the work; and that any improvement in caregiver knowledge, skill and behaviour would result in a reduction of the difficult behaviours demonstrated by residents (Sweetnam,1999).

3.3 Curriculum Mapping

The second major task carried out in preparation for developing a curriculum was to review and assess existing curricula. In the late 1960s, Morrissett, Stevens and Woodley (1969) proposed a systematic means for analyzing curriculum materials and structured teaching-learning transactions. Their model is based on three components of any structured learning situation: (1) inputs or the ingredients -- teachers, learners, materials, and context -- that go into a structured learning situation; (2) transactions or the events that occur within and among the inputs; and (3) outcomes or the resulting changes which can be attributed to the structured learning situation. If the curriculum developer choses to focus on making changes in one of the four basic inputs, then the other three inputs would be considered as antecedent conditions, or elements of the teaching-learning situation which would be taken as given and not subject to special attention or to manipulation.

For this study, the focus was placed on the development of teaching and learning materials. Therefore, the characteristic features of the participants in the training, of the facilitator, and of the context in which the training would occur were considered as antecedent conditions. These features, some of which were identified in the needs assessment activities. needed to be taken into account in developing the materials; and the major focus of the curriculum development activity would be on designing a rationale, objectives, teaching strategies, learning materials, and assessment methods suitable for the antecedent conditions and the planned outcomes. Morrissett, Stevens and Woodley (1969) have argued that the best method for understanding the major features to be included in new curriculum materials is to analyse existing curriculun materials.

With this advice in mind, I conducted a library search and talked to numerous persons in both the Alzheimer Society (Canada) and the Alzheimer's Association (U.S.) to identify as many existing curricula on the topic of Alzheimer's Disease as possible. By the end of the research gathering phase, I had accumulated 15 curricula that had been used to train a variety of caregivers who work with individuals who have Alzheimer's Disease and related dementia. Four of these curricula were not directly related to training caregivers and were excluded from the assessment and comparison process. The following eleven curricula were chosen for their applicability to the target audience for the training I was planning and for their relevant content.

- *Training the Trainer: Building Creative Caregivers* (McGillick, 1997)
- *Dementia in Long Term Setting: Training for Dignity* (Hanser, 1994)
- *Just for the Summer* (Alzheimer's Disease and Related Disorders Association, 1991)
- *For Those Who Take Care: An Alzheimer's Disease Training Program for Nursing Assistants* (Helm & Wekstin (1995)

- *Keys to Better Care: A Training Program for Nursing Home Staff Caring for People with Alzheimer's Disease and Related Dementia* (Consult Services Incorporated, 1993)

- *Provider Intensive Workshop: Training for Professional Caregivers* (Alzheimer's Disease and Related Disorders Association, 1993)

- *Caring for People with Alzheimer's Disease: A Training Manual for Direct Care Providers* (Andresen, 1995)

- *Optimum Care of the Nursing Home Resident with Alzheimer's Disease: Giving a Little Extra* (Gwyther & Ballard, 1990)

- *Alzheimer's Disease — Pieces of the Puzzle: A Training Program for Direct Service Staff and Family Caregivers* (Barba, Ehrmann, Koff, Myers, Parker & Scott, 1990)

- *Activity based Alzheimer's Care: Building a Therapeutic Program* (Alzheimer's Disease and Related Disorders Association, 1997)

- *Alzheimer's Disease: Care at Home* (Alzheimer Society of Canada, 1996)

In order to review these materials, a number of criteria with specific parameters were selected to organize the process. I developed these criteria based on my initial reading and analysis of the curricula and on my understanding of adult learning principles. The materials were assessed from three perspectives: the applicability to the caregiver, the needs of the facilitator, and the investment required by the organization.

From the caregiver perspective, each curriculum was examined in terms of:

- Content — Curricula were evaluated according to the usefulness, accuracy, originality and relevance of the information to the performance of caregiver's work. Curricula were also evaluated in terms of what material was not provided that should have been.

- Variety — Since learners take in information, select relevant information and incorporate new material into existing knowledge in personal and unique ways, the curricla were evaluated according to the variety, originality, appropriateness and quality of the learning tasks employed.
- Evaluation — Curricula were evaluated on the basis of whether learners were given an opportunity to share what they had learned, examine whether the knowledge they had gained was accurate and/or to question the relative success of newly acquired knowledge and skills. Curricula were also assessed according to the kind and quality of evaluation segment.
- Language — The results of the needs assessment indicated that most caregivers have a high school reading level. Curricula were evaluated according to the complexity of words and sentence structure used in handouts, learner instructions, and lecture activities.

From the facilitator's perspective, each curriculum was examined in terms of:

- Flow — Activities in a learning environment should follow a logical progression with one learning event leading or building upon another. Each curriculum was assessed in terms of how well one activity led to another, how well one module led into the next, and how information presented in one module built upon the information presented in the previous module.
- Variety — In order to address different learning styles and to hold the interest of the participants and the facilitator, a facilitator needs to use a variety of training techniques. Curricula were assessed according to the variety and quality of teaching

techniques employed. Assessments were also based upon an attention to the physical and emotional environment through the use of music, voice intonation, and alternative facilitation personnel.

- Clarity — Clarity refers to the simplicity and accuracy with which instructions are written and material is presented. Curricula were evaluated for the clarity of facilitator's guidance and facilitators' instructions to the learners.
- Readability -- If the curriculum is actually used to teach from in front of a group of learners, the facilitator needs to be able to see the words, read it and follow the instructions as they are written. Curricula were assessed in terms of whether the material was aesthetically pleasing to the eye with a font size that was visible from an upright position. The material reviewed also had to make sense, be interesting and be easy to read.

From the organizational perspective, each curriculum was examined in terms of:

- Cost — Curricula were evaluated depending on the price of the curriculum (if available), amount of logistical support (room availability, learner supplies and audio-visual equipment), costs incurred for time off for personnel for organization and facilitation and cost associated with time off for learner participation.
- Time commitment — Curricula were evaluated in terms of the expenditure of hours spent in organization, preparation, attendance and evaluation by learners and facilitators.
- Value added — The aim of providing training is to improve the quality of care provided by the caregiver to those that they care for. Depending on the value of the

material to the learners, the amount of work for the facilitator and the financial expenditure of the organization, the curricula were evaluated to determine if the training was worth the effort.

For the benefit of the reader, the assessment of the eleven curricula is summarized in Table 1 (see p. 53). A description of the assessment of each curriculum and additional relevant information is provided in the next eleven sub-sections.

3.3.1 *Training the Trainer: Building Creative Caregivers*

This curriculum was written by the staff of the St. Louis, Misssouri Chapter of the Alzheimer's Association (McGillick, 1997). It primarily uses material that is mass produced by the national office of the Alzheimer's Association, and is easy to access and readily available. The curriculum is comprehensive and includes eleven modules, three of which are meant to be used by facilitators to enhance their presentation skills. It is one of the few curriculum reviewed that contained information about the teaching process and its application to adult learners.

Applicability to the Caregiver

No distinction was made between the various kinds of caregivers. This curriculum is meant to be used with a variety of caregivers whether they are professional staff in long term care, family caregivers, volunteers, or home-care paid staff. Therefore, more content areas are included than are useful to those who work in a long term care setting. No evaluation methods are included in this curriculum. The material and the handouts intended for the caregivers are not appropriate for their academic level. Many could be used by nurses and doctors, social workers and the like. The curriculum is

Table 1 - Review of Existing Curricula

Title		Applicability to Caregivers				Needs of the Facilitator				Organizational Investment		
		Content	Variety	Evaluation	Language	Flow	Variety	Clarity	Read	Cost	Time Commitment	Value Added
3.3.1	*Creative Caregivers*	***	**	N/A	*	*	**	**	**	$	***	**
3.3.2	*Training forDignity*	*	****	***	**	****	****	****	***	$$$	**	***
3.3.3	*Just For the Summer*	N/A	****	****	****	****	****	****	****	$$	****	N/A
3.3.4	*Those Who Take Care*	*	*	**	**	*	*	*	***	$$	***	**
3.3.5	*Keys to Better Care*	**	*	*	*	*	*	*	*	$$$	*	*
3.3.6	*Provider Intensive Workshop*	*****	*****	*****	*****	***	*****	***	***	$$$	****	****
3.3.7	*Direct Care* Providers	**	**	***	**	*	**	*	**	$$	***	***
3.3.8	*Giving a Little Extra*	****	**	**	****	**	**	***	*****	$	***	***
3.3.9	*Direct Staff and Family Caregivers*	***	***	N/A	***	**	***	**	**	$$$	**	***
3.3.10	Activity Based Care	***	*****	*	*****	*****	*****	*****	***	N/A	***	****
3.3.11	*Care at Home*	****	*****	****	**	****	*****	****	****	$$$	*****	****

***** Excellent **** Very good *** Average
** Below average * Poor N/A Not Applicable

$ Affordable $$ Expensive $$$ Too expensive composed of disparate parts hooked together, but generally based on a common theme. The learning strategies are based primarily on didactic methods such as lectures; and occasional case studies that employ alternate learning methods.

Needs of the Facilitator

The curriculum reads like a resource book with a number of tools to be used depending on the skill level and the teaching style of the facilitator. In that sense, there is really no flow or continuity, except by common theme. It appears that the format is meant to be didactic and that learner input is expected to be minimal. Each module contains a helpful bibliography that adds background reading to the content.

In terms of clarity and ease of following, there is little to differentiate one page from another. Margins are very narrow making the material look congested and difficult to read. There are also few font adaptations, markers or icons to break the monotony of text.

Because the material has been culled from a number of different sources and authors, it is difficult to follow. Some pages are filled front and back, while other page backs are blank. Despite layout and format problems, I found some articles to be excellent. In addition, drawings and potential learner handouts are provided. This curriculum exists as a large resource manual from which a facilitator could make his or her own curriculum. Therefore the success of whatever is taught from this curriculum rests largely on the strengths of the facilitator and his or her teaching abilities.

Lesson plans, learner objectives, and learning activities are included for each module. This layout works very well as an outline but not very well as a complete lesson plan, and would work best if the group leader is a very skilled facilitator. The outlines are the type of plans that teachers/facilitators would make for themselves for their day-to-day work. It is not the type of plan that would be useful to a neophyte trainer.

Organizational Investment

This curriculum would require a signifigicant time investment to prepare for individual training sessions. Each module offers suggestions to follow but ultimately the facilitator must plan how the time is to be used beforehand. Additionally, costs of photocopying would be substantial since there is little learner-generated material. Much of the teaching time would be spent either teaching by lecture or explaining handouts that would be used to supplement lectures.

It is difficult to assess cost to the organization in terms of release time from work for participants as there is no indication of the time required for each activity or of the appropriate class size.

3.3.2 *Dementia in the Long term Setting: Training for Dignity*

This curriculum was written by Suzanne Hanser (1994) for the Alzheimer's Association of the Greater San Francisco Bay Area Chapter. It was created for use within long term care settings without differentiating between types of health-care professionals (e.g., nurses, therapists, etc.) in the workplace. It was developed to be used in-house, incorporating selected staff from all spectra of care and to be delivered within the confines of staff shift changes and resident/staff ratios. All staff are required to attend and if absence is unavoidable, make-up sessions are arranged.

This curriculum is impressive because of its conciseness and organization. There are seven modules with additional sections dedicated to pre and post assessments. There is also a reference section which includes 13 "Just the Facts" information sheets published by the Alzheimer's Association to be used as references and handouts. The reference section includes three videotape suggestions.

Applicability to the Caregiver

Because the curriculum was developed to be used without regard to the needs of a particular occupational group, there are inherent difficulties with unrealistic expectations. Forcing caregivers to interact with nursing management in a learning environment may be a good idea in theory but may not work as well as expected in practice. Some examples of realistic difficulties that would be encountered in this kind of training include: fear of judgment over academic performance, fear of reprisal for differences of opinions, reluctance of supervisors to interact with supervisees, and difficulty addressing greatly disparate learning needs.

The curriculum includes a number of excellent learning opportunities that take advantage of various learning styles. The learner has the opportunity to brainstorm, share in group settings, face experiential learning situations, watch videotapes, and react to each learning session by way of post-session evaluation forms. The expectations of learner achievements are very clear and there are many opportunities for caregivers to use their caregiving experiences.

Needs of the Facilitator

Training for Dignity is very well laid out and easy to follow. Plans are clearly defined. Material is organized so that the facilitator is aware of the objectives, the materials needed, and the progression from one activity to another. Activities are numbered, as are the pages. Estimated time frames are given for each activity as well as an elapsed time indication -- a great addition when timing is crucial. Continuity is evident from one module to another. Similar formats are used with each session ending with evaluations. One evaluation form is given to the learners, while the other captures the reaction of the facilitator. However, little time is given for learners to complete their forms and no time is given for completing the facilitator evaluation. As a result, meaningful data may not be obtained from this process of evaluation. As Knowles (1980) has suggested, information gleaned from such evaluation forms may be more a reaction than a reflective comment on the learning.

Organizational Investment

Use of *Training for Dignity* requires an extended organizational commitment to training. The overall objectives of the training state that "the effectiveness of long term care is enhanced when all levels of staff learn and apply the skills and techniques included in this training" (Hanser, 1994, p.5). Moreover, since all staff are required to attend, staffing modifications, and room and time allotments are obligations undertaken by the organization. No indications are provided about the number of learners per session, so cost and staffing are difficult to predict. This curriculum awards certificates to the facilities which complete staff training, but offers no recognition to the individuals who complete the training. The curriculum presents a very ambitious endeavour considering the objective of training all staff in all seven module areas.

3.3.3 *Just for the Summer*

This curriculum was produced by the Alzheimer's Association (Alzheimer's Disease and Related Disorders Association, 1991), with recognition given to the Los Angeles Chapter for its contribution. It was chosen to be reviewed for several reasons. It demonstrates how particular teaching methods could be clearly organized to suit the needs of a specific learning group.

Just for the Summer primarily targets family education, specifically the teenagers in families that are affected by Alzheimer's Disease. In addition to providing knowledge, the curriculum was developed in the hope that it would inspire volunteer recruitment and public service amongst teens in general. Nevertheless, the manual explains that the curriculum would be applicable to other settings, including churches, colleges, and community youth groups such as Junior Achievement, 4-H, and Boy and Girl Scouts.

Applicability to the Caregiver

The curriculum is based on reviewing a videotape followed by opportunities to role-play, solve cases, and discuss issues of dementia with peers. Handouts for the learners are age and academically appropriate with graphics and bolded text to hold visual interest. The pre/post test is based on a true/false questionnaire. Alternate evaluation processes are based on discussion questions and case studies.

Needs of the Facilitator

Materials included for the facilitator are excellent. The manual outlines a number of 'lesson plans' which detail activities that can be employed as well as time requirements. Background readings are included in the text as well as a comprehensive bibliography. The inclusion of reference material saves considerable time that would otherwise have to be spent searching for materials. Brief descriptions of each activity are provided. These instructions are so brief that only trained facilitators could use them with ease.

The format of the curriculum is clearly laid out and easy to follow. The three-inch margins and visual white space make the text uncrowded and easy to read.

Organizational Investment

Organizational investment is not a factor with this curriculum. Participants are not employees who must be granted release time. The inclusion of handouts, reference material, activity descriptions and lesson plans in the package means that minimal time will be needed for preparation provided the teacher/facilitator is experienced.

3.3.4 *For Those Who Take Care: An Alzheimer's Disease Training Program for Nursing Assistants.*

This curriculum was written by Helm and Wekstin (1995) at the Alzheimer's Disease Research Center of the Sanders-Brown Center on Aging at the University of Kentucky. This centre is one of the 27 Centers of Alzheimer's Disease Research facilities found throughout the United States funded by the National Institute on Aging.

The manual was created on the premise that those who deliver care most directly to persons with Alzheimer's Disease are those most able to positively affect the quality of life of those individuals. The developers maintain that a better trained assistant delivers a better quality of care. Their philosophy of care is focused on the resident rather than on the tasks of caring for the resident. This pattern of thought is consistent with the 'psychosocial' philosophy discussed in Chapter Two.

Applicability to the Caregiver

The curriculum has been divided into seven modules with the first module directed toward normal aging. In fact, there are constant references throughout the manual that contrast normal aging to aging with dementia. The learner content is not academically appropriate and many of the handouts and pre/post-tests use language that is more appropriate for college graduates than for caregivers with only a high school education. Furthermore, handouts are visually uninspired, reading as if they were created as medical text book material. The material is presented for auditory learners, with little apparent understanding of different learning styles (e.g., auditory vs. visual learners) or adult learning principles. The curriculum does not adequately address learner needs and goals.

The evaluations are based on pre- and post-test results using true/false questions. This format is used to develop tests to be completed at the end of each module. There is little time included for discussion with peers or personal reflection. Such evaluations are based on short-term recall and have limited usefulness as a tool to inspire better care.

Needs of the Facilitator

The material is well organized, well laid out, and easy to follow. For experienced trainers, teachers, and facilitators of university level courses, the curriculum would be quite appropriate. The language choices are surprisingly difficult, even though the authors allude to the low grade reading abilities of some caregivers and state that they have taken this into consideration in the preparation of materials.

Few experiential and sensory activities are included in the curriculum to add variety to the didactic teaching method used predominantly throughout. Not enough information is provided to adequately prepare facilitators or participants in the few experiential activities that are included. Participants are not informed about what to expect, how they might feel or how they should react to various activities. No debriefing opportunities are provided following emotionally charged activities. Good adult learning principles state that adult learners do better when they are prepared for what will happen in a learning activity and when they can talk about their experiences following emotionally charged activities (MacKeracher, 1996).

A number of overheads support the lecture materials. They are easy to read but are unimaginative. The overheads appear to be a continuation of text rather than points to be clarified by the facilitator or to arouse curiosity or thought in the learner.

Organizational Investment

The writers have tried to adapt the curriculum to the needs of facilities by offering different scheduling options. The curriculum recommends that caregivers be required to attend all seven sessions, which presents difficulties for staffing arrangements and make-up sessions. Class size is not addressed which may make the organization and preparation of sessions difficult.

For some facilitators, the use of an academic, true/false, evaluative tool is reassurance that training for caregivers works. Depending on the objective of the facility, the type of training implied in such evaluative techniques may suit their needs admirably. However, if the facility is searching for a way to improve how caregivers think about residents and about the quality of care that they deliver, the true/false testing is not suitable.

This kind of curriculum requires excellent teaching and facilitating skills, something that is often lacking in those who do training in long term care facilities. Careful attention needs to be paid to the skills of the trainer since the aim of this curriculum could be undermined drastically through well-intentioned, but inexperienced, facilitators.

3.3.5 *Keys to Better Care: A Training Program for Nursing Home Staff Caring for People with Alzheimer's Disease and Related Dementia.*

This curriculum, published by Consult Services Incorporated in Narbeth, Pennsylvania (1993), was difficult to access. Consult Services Inc. is a private company and was reluctant to let the manuals be reviewed for academic purposes. A copy was finally obtained through the American Veterans' Association Hospital Library where it had been purchased for use for their large dementia care programs throughout the United States.

Applicability to the Caregiver

This package defines its audience as all direct service staff including: nurses aides, licenced practical nurses, registered nurses, occupational therapists, physical therapists and others. By attempting to appeal to such a wide variety of occupational groups, the learning needs of specific groupd are ignored. This material does not appear to address the needs of direct caregivers.

This curriculum is text-based, meaning that most of the material in the manual is included as actual text that is read to (or by) the learner. This type of auditory presentation is likely to cause some caregivers to lose interest quickly. When videos are presented, the facilitator's role is to offer an explanation to further augment learning. The handouts are complicated, comprehensive, unimaginative, lengthy, and the type font is too small. Lists of complex conditions and diseases are of little use to caregivers.

The evaluation segment of this curriculum is of the true/false type. Poor readers may have difficulty with it. The test is taken home by the learners who have time to reflect on their learning. Additionally, time is given in the lesson plan of each module to discuss the previous module's test.

Needs of the Facilitator

Despite the preponderance of the lecture teaching method, other strategies are also incorporated. Videotapes of actual care practice in real facilities offer a realistic view of how others provide care. In some of the 13 modules, family guests are brought into the learning. In other instances, efforts are made to initiate large group discussions.

The modules are very difficult to read; the material is cramped for space and the margins are too narrow. It appears as if the material is intended to be read to the learners from start to finish. An experienced facilitator would throw out the text and use only the outline to deliver the material; inexperienced facilitators might be tempted to read the text from beginning to end. The material is written in such a way that it would be difficult to vary from the text or to stop and start again in the middle of the text.

Organizational Investment

At $2,500 (U.S.), the curriculum package is expensive and few facilities would be able to afford it. Further, its lack of availability through alternative sources makes it improbable that facilities without a large training budget would use it. Additionally, thirteen modules would require a huge investment in personnel and organizational strategies to support the use of this comprehensive training endeavor.

3.3.6 *Provider Intensive Workshop: Training for Professional Caregivers*

This curriculum was developed by the Atlanta Chapter of Alzheimer's Association (Alzheimer's Disease and Related Disorders Association, 1993) for their training staff to provide in-service training for caregivers. The package modules include: an overview of Alzheimer's Disease; communication and behavioural challenges; impact of the disease on the family; and care strategies related to hygiene, safety, and nutrition. This package is a 'no frills' basic resource book that has been prepared with adequate content knowledge for those who care for someone with Alzheimer's Disease but without the explanations and descriptions that would typify a more facilitator-friendly document.

Applicability to the Caregiver

The material contained in this manual is appropriate for most caregivers. The module topics are pertinent to caregivers and the material is written so that it is easily understood. A variety of instructional methods are used throughout the manual; however the poor instructions for facilitators suggest that little benefit would accrue to the learners in these activities. No efforts are made to inspire reflection, nor are there any module-by-module evaluative measures.

A pre/post-test is used to evaluate the recall of content, presumably with the intention of proving that learning has occurred. Differences in pre- / post-test scores may indicate a change in knowledge about the disease but has little to do with change in the quality of care delivered to the person with Alzheimer's Disease.

Needs of the Facilitator

The manual uses text boxes, bullets, and bolded text. It is extremely difficult to tell which materials are instructional statements to be spoken to the learning group and which are background reading for the facilitator's own use. Despite a variety of interesting activity suggestions, very little information is provided to adequately prepare the facilitator for the material to be taught.

Overall time frames are given for each module. However, how the time is allocated within the module is unknown. The facilitator is left to figure out what material is important, how long it should take, what instructions should be given, and what material should be covered. It is difficult to read since the guidelines are portrayed in a confusing manner. A great deal of effort is recommended to elicit learner response.

However, asking learners how they 'feel' after every activity is, in my opinion, neither productive nor conducive to meaningful learning. Periodically the recommended activities are counter-productive. For example, in the communication module, the learning event is a story that is read to the participants about how a mother relates to her kindergarten-aged son. The point concerning the fact that how one communicates is just as important as what one communicates is well taken; however, the mother-son context is completely inappropriate. Practitioners of dementia care work need to be encouraged to overcome the myth that people with Alzheimer's Disease revert back to childhood. The mother-son activity, by inference, perpetuates this myth.

Organizational Investment

The use of two-hour time blocks is consistent with results obtained from my surveys. However, this curriculum is not clear about what is to be accomplished within this time frame. Class size, organization, and facilitation requirements are not addressed. Significant time would be needed to prepare overheads, since none are included, and to develop suitable lesson plans.

3.3.7 Caring for People with Alzheimer's Disease: A Training Manual for Direct Care Providers

This curriculum was prepared by Gayle Andresen (1995). Packaged in a very unusual manner, the curriculum resulted from a collaboration of no less than six partnerships between two large groups of continuing health care educators.

Applicability to the Caregiver

This curriculum was written for nurses, nursing assistants, social workers, dietitians, activity directors, and all other staff having any contact with people with Alzheimer's Disease. While the intent of reaching such a broad base is admirable, the possibility of writing curriculum that is appropriate for such a wide range of workers is impossible. Between groups there are widely varying degrees of skills, role expectations, responsibilities and academic backgrounds. The language, learning activities, and content that are appropriate for one group may not be appropriate for another group. For example, sections concerning medication for depression and behaviour amelioration are inappropriate for front-line caregivers and housekeepers. Some of the material is confusing because it includes content that, upon reading, is clearly more appropriate for family caregivers than for professionals in long term care facilities.

Each module is completed with a content-based test in multiple choice or fill-in-the-blank format. Each module also includes an evaluation questionnaire to be completed just prior to the end of the session. This questionnaire concerns the quality of the instruction and appropriateness of the content.

Needs of the Facilitator

Unlike other curricula, *Caring for People with Alzheimer's Disease* devotes a section to adult teaching and learning principles. This section is included because there are no instructions for teaching the modules other than stating the objectives of each module. The adult learning and teaching material that is included is content based and may be background reading for the facilitator, or in some cases may be used as handouts. No guides are provided about individual teaching techniques or activity progressions. This format is appropriate only for those who are experienced trainers since each module in the package seems to serve as a content resource with the teaching methods determined by the facilitator

The Instructor's Guide mentions that the modules are meant to be used in one- or two-hour sections; however, no time indicators are made throughout the modules. The manual is easy to read and appears comprehensive, although as a teaching tool there is little to guide the facilitator.

Organizational Investment

There are no instructions for how to organize a group of learners, how to determine group size, or how to prepare the learning environment. Facilitators will need to invest considerable time to prepare for each session, but little is known of the organizational commitment since little information is given. Overheads must be prepared as only paper copies are given, and all handouts must be prepared and photocopied for individual use.

The last difficulty that plagues this otherwise good curriculum is the manner in which it is packaged. The manual is actually a six by eight-inch bound book. This format makes photocopying next to impossible and the suggestions for cutting along the dotted line to access overheads is, in my opinion, unrealistic and unusable.

3.3.8 *Optimum Care of the Nursing Home Resident with Alzheimer's Disease: Giving a Little Extra*

This curriculum was written by the prolific and respected authors, Lisa Gwyther and Edna Ballard, of Duke University (1990). This curriculum has excellent content material with well chosen topic areas that are appropriate for the target population. It has a single companion video that depicts a day in the life of a caregiver. The video is unusual and drives home the point that caregiver work is both hard and invaluable.

Applicability to the Caregiver

The content of the curriculum is easily read and is appropriate for the needs of direct caregivers. Much of the material is very practical and examples are continually drawn from real life situations and family and caregiver comments.

Needs of the Facilitator

This curriculum is actually an excellent resource manual. There are a number of topics that have been expertly summarized so that the language and content is appropriate for the target audience. The clarity that is apparent in the writing arises from a vast practical working knowledge of the topic.

The curriculum is very well organized into three separate areas that cover an overview of the disease, the transition to the nursing home, and a number of behavioural manifestations. The section of behavioural manifestations includes a survey of a number of difficulties encountered by caregivers and suggestions to ameliorate situations. It also includes information about activities, safety, and a large number of appendices that are suggested as possible handouts. However, the handouts read like pages from a textbook with little to make them visually appealing. The curriculum also actively incorporates material that is pertinent to families and includes a section that refers to the poorly addressed needs of those in later stages of dementia. A sample evaluation form is included to determine reaction to and usefulness of the training.

However excellent the content is in this manual, it is not a teaching manual. How the training should be arranged, what material to incorporate, what to leave out, what time frames are involved, instructions, and teaching guides are all areas that are simply not addressed. As if to rectify this oversight, a foreword is included that contains principles for training and suggestions for material and props.

Organizational Investment

Despite the lack of any teaching guidelines, the importance of logistics is mentioned including such factors as room size and layout, lighting, seating and comfort. These topics are often neglected in other curricula. Little mention is made of the administrator or management investment. No mention is made of staff recognition for training, staffing concerns during training, or guidelines for who or how many should attend training. The facilitator must make a large investment in time because training methods need to be determined, individual module objectives set, method(s) of evaluation ascertained, handouts prepared and photocopied, activities decided on to permit logical flow, and a method of learning progression identified.

3.3.9 *Alzheimer's Disease – Pieces of the Puzzle: A Training Program for Direct Service Staff and Family Caregivers*

A team of six authors developed this curriculum at the Arizona Long Term Care Gerontology Center at the University of Arizona (Barba, Ehrmann, Koff, Myers, Parker & Scott, 1990). The curriculum incorporates five specifically-produced videotapes. This comprehensive manual was site-tested with over 700 participants. The five videotapes can be used as stand alone modules for those who desire self study. The curriculum is comprehensive in the sense that all materials used in training are included in the package.

Applicability to the Caregiver

There is more content material included in *Pieces of the Puzzle* than a direct caregiver needs to know. Despite the complexity of some of the topics, each is explained simply and at a level that the average reader could understand. For example, the module that concerns medications, which in other curricula quickly spirals into pharmacological language, has appropriate caregiver learning objectives. Those learning objectives are targeted at improving observation and reporting skills for possible side effects or toxicity in those being cared for. Unfortunately, the accompanying handout has a dizzying array of diagnoses, medications and possible side effects that is far beyond the needs or abilities of caregivers.

Throughout the manuai there are a variety of teaching techniques suggested to appeal to a spectrum of learning abilities. Role playing, large group discussions, large group activities, watching videotapes, visualization and experiential activities are used periodically in many modules. Additionally, the authors emphasize the variability of learner strengths and the need to adapt and remain flexible to accommodate learner needs.

Needs of the Facilitator

Pieces of the Puzzle is more 'facilitator friendly' than most other curricula. The introduction outlines each module, gives guidelines for training, and explains how the videotapes are to be incorporated into the curriculum. The authors emphasize the need for facilitator preparedness and the importance of a sense of humour and enthusiasm for the topic.

Each module is given an overall time frame but individual times for activities are not given. The material is clearly laid out and has enough white space to make the material easy to read. The text uses a larger font, bolded text and text boxes to indicate activities with participants. The instructions for activities such a large group discussion are very brief and probably more appropriate for an experienced facilitator. Despite the numerous points at which learners are asked to participate, the curriculum is again one that is primarily didactic in nature. The text of material to be covered is included along with learner instructions. This style of presentation is, in my opinion, nearly impossible to use or follow when actually teaching, unless the facilitator is reading the material to the participants.

Organizational Investment

All of the materials that are required to teach this curriculum are included in the teaching package. The parameters for class size, time, location, and equipment needs are supplied. No method of evaluation is provided, nor is the topic even addressed. After the objectives of each module are clearly stated, the content material reverts to resource type text.

The package is expensive to purchase and the intent is for the learner to come away with a 'study package' that is fairly extensive. The cost of paper copying, video equipment, etc. would quickly spiral out of reach of many facilities. In terms of time, 16 hours of training is an extensive commitment from both personnel and management Substantial time is required for the facilitator to prepare lesson plans and/or outlines.

The authors state that the order in which the modules are presented can be modified because they are interdependent and inter-related. The first module concerns stress and there is no clear relationship to the second module on disease overview. The module concerning medication appears between safety and activities of daily living, in the middle of the curriculum. Little reference is made throughout the curriculum that explains how one module is connected to another.

3.3.10 *Activity Based Alzheimer Care: Building a Therapeutic Program*

This curriculum is one of three that have been created by the Alzheimer's Association (Alzheimer's Disease and Related Disorders Association, 1997). One of the five-year mandates in the Training and Education Department of the Alzheimer's Association is a concentrated effort to develop curricula to train selected audiences in the delivery of quality dementia care. Activity Based Alzheimer's Care (ABAC) represents their third curriculum and focuses on the delivery of meaningful care through the broad concept of meaningful activities. The concept logically targets recreational therapist professionals but the rationale strives to include caregivers as a very important part of the team that delivers quality dementia care.

Applicability to the Caregiver

The curriculum uses language and structure that is appropriate for all learners including caregivers. The authors go to great lengths to ensure that definitions are clear and objectives are stated in language that is easily understood. Many activities are included that are meant to stimulate interest and incorporate a number of learner strengths. Learners have the opportunity to do small group work, large group discussion, experiential activities, visualization exercises, and table 'hopping' -- a process whereby learners who sit in small groups at round tables have the opportunity to move to another table to improve their ability to network and learn from others in a controlled and 'safe' environment.

The evaluation tool was recently revised to move away from an assessment of the content learned to a more reflective learning tool. The participants in the pilots of this curriculum were unequivocal in their comments concerning the evaluation segment of the training. They stated that there was little to be gained from regurgitating the words used in their training manuals. What they wanted was a way to express what they learned in terms related to their own caregiving practises.

Needs of the Facilitator

The material in the curriculum is very well prepared and obviously incorporates practical facilitation techniques. The material is prepared so that it is not read to the participants. This curriculum is the only one reviewed that is designed so that it is possible to facilitate training, use the manual, and not have to read the material to the learners.

The modules are designed with interconnections so that each builds on the previous modules. There is good use of bold text, text boxes, and symbols to designate the use of an overhead, participant manual, or handout. There is ample white space and wide margins which would accomodate hand written facilitator notes. Activities are also given symbols and time frames. Unfortunately, the amount of material to be covered does not correspond to the amount of time given. Since this fact occurs early in the first module in the training, the lack of time to complete training becomes omnipresent throughout the training day.

The training is meant to be delivered by two facilitators. This proves much less taxing to the facilitator and is much more interesting for the participant. Sufficient breaks are incorporated into appropriate places between each module and each module begins with an icebreaker that relates to the material which follows.

Organizational Investment

The curriculum cannot be purchased at this time. It is being taught throughout the United States by a number of trained professionals employed by the Alzheimer's Association. It requires an organizational commitment to send personnel to the training. This requires a different type of organizational commitment than training that is provided at the facility by an in-house trainer through purchased training packages. This kind of training is very expensive. However, despite the travelling and registration costs, there are a number of advantages, one of which is the networking encouraged by the program. In my opinion, the quality of training is excellent, the content is current, the take-home documents are useful, and the benefits of finding out what others are doing and bringing the ideas back home greatly outweigh the costs. Furthermore, one module specifically addresses the issue of teamwork and how to incorporate what the participant has learned at the workplace. The curriculum not only aims to improve the delivery of a better quality of care, but also endeavors to train participants to act as facilitators for co-workers. Thus the learners return to their workplaces with better caregiving skills, well acquainted with participants from other facilities who can help them solve problems, and are also empowered to act as a facilitator/trainer/mentor for the improvement of other caregivers within their facility.

3.3.11 *Alzheimer Disease: Care At Home*

This curriculum (Alzheimer Society of Canada, 1996) was created with the input from many branches of the Alzheimer Society, HomeSupport Canada and a large number of individual contributors. It was developed as a result of needs assessment completed by 281 agencies and 53 home support workers, plus 681 agencies who completed a pre-survey. Of all the curricula reviewed, *Care At Home* represents the largest collaboration and the most extensive research in curriculum development in either the United States or Canada. The result is one of the best curricula from the point of view of learner appropriateness, variety of teaching and learning strategies, attention to cultural and ethnic diversity, and content applicability.

Applicability to the Caregiver

The content of this curriculum is directed toward caregivers who are employed in the private homes of those with Alzheimer's Disease. Both the fourth and fifth modules, *Working with Families* and *The Home Environment*, contain a number of training issues that are not appropriate for learners who work in long term care facilities. Despite the obvious limitations which preclude its usage in institutional settings, the language is appropriate for the academic levels of caregivers and a vast array of learning activities have been included to accommodate a variety of learning styles.

Each module contains an evaluation form with true/false responses. The authors suggest that it can either be used as a evaluative or group review tool. There are also separate instructions for self-study and self-evaluation for those who want to use the curriculum in that way.

This curriculum is very comprehensive. It includes seven modules with a number of topics included in each module. The binder that houses the learner materials is large and cumbersome. Adding videotapes to the material makes a large and awkward package to carry. The participant manual on its own is too large to be a resource which could be used at work. I believe that it is meant to be used and passed on to the next participant. A number of pages look like possible handouts but are not labelled as such. It would be up to the individual facilitator to decide what to copy and what to leave as text.

Needs of the Facilitator

This curriculum includes an entire section that thoroughly prepares the facilitator for training. The authors suggest that the learner and the facilitator binders are needed to be used at the same time while facilitating since none of the learner materials are included in the instructor's binder. This creates a very awkward bundle to manage during training sessions. Additionally, the page numbering is inconsistent with each topic within each module having its own set of page numbers.

The facilitator receives instructions on how to facilitate a number of teaching techniques from role playing to group discussion. A bibliography of training techniques as well as a bibliography for each module is included. The authors have also included an evaluation form to be used at the end of each module to collect feedback from the participants.

Each module contains a chart which outlines the topic objectives, the materials and time required. It also states the teaching strategies used and clearly outlines, for the facilitator, the material, with suggestions for activities and activity options. Each topic ends with a reinforcement type of activity. Time for each topic in each module varies with total time per module, but generally requires approximately two hours. Each topic is arranged as a stand alone topic. No information is provided to determine where breaks should go. Although topics are related by subject matter in the modules, there are really no bridges from one topic to another.

Despite the quality of instruction and the variety of teaching methods, the curriculum needs visual improvements. Type font and white space is more than adequate, but the readability would be greatly enhanced by the use of text boxes to enclose group activities and instructions. The curriculum would also benefit by the addition of some numerical or alphabetical order to activities within each topic since there does not appear to be a break or a 'finish' to one activity before another one starts.

Organizational Investment

With eight modules, including 27 topics and an introductory module, *Care At Home* represents a comprehensive commitment in terms of time, personnel, logistics, and money from the organization, facilitator/trainer, and participant perspective. The self-study aspect of this curriculum must be viewed as a realistic alternative. Copying costs would be prohibitive if all participants were to receive participant manuals. Since no overheads are included with the package, time and money would need to be devoted to their development. Despite the extensiveness and the quality of the *Care At Home* curriculum, it would, realistically, have to be adapted and condensed in order to satisfy participants' needs and administrative concerns.

3.4 Summary of Curricula Mapping

When all eleven curricula were compared and contrasted, several themes emerged. I had been warned that many curriculum writers were guilty of reinventing the wheel. Indeed, the content for many of the curricula was identical. For all but three, the training materials included resource information that read like text books. They were not training materials at all, but rather background reading for training activities.

The use of most of these curricula for training purposes would be impossible without considerable modification by an experienced facilitator. Most called for reading and primarily lecture-type teaching methods from the facilitator and strong listening comprehension skills from the learners. Not only is this type of teaching extremely boring for a facilitator, it is nearly impossible for caregivers to learn successfully. Little attention was paid to adult learning principles that call for a variety of teaching strategies that appeal to different kinds of learners, a concentration on practical skill acquisition, group discussion, personal reflection, or opportunities for application of new skills.

What was lacking in all but three curricula was a working knowledge of the learning needs of the caregiver. Unfortunately, the three curricula that appropriately addressed learner needs were not exactly appropriate for caregivers in long term care. *Just for the Summer* focused on high school students, *Activity Based Alzheimer Care* primarily addressed activity therapists, and the *Care At Home* curriculum targeted caregivers who provide dementia care in private homes.

The curricula review proved vital from a developmental perspective. In addition to confirming what content was necessary, the review was indispensable for illuminating the areas in various curricula that were not addressed. I would not be 'reinventing the wheel' if I applied the plentiful content material to the real area of unmet need -- caregiver-specific curriculum. Like Morrissett, Stevens and Woodley (1969) I discovered that although content is important, there are other necessary inputs in any educational endeavor, and these include the learners, the facilitator and the organizational context.

3.5 Curriculum Development

With a large number of curricula in hand, a vast accumulation of literature, and the results of Canadian and American needs assessments at my disposal, the creation of *Pride in Alzheimer's Care* proceeded slowly. I seemed in danger at all times of drowning in resources that dealt with content, and in being overwhelmed with my own desire to be creative. My aim was to create a learning environment that would inspire a change in behaviour by emotionally, sensorily and cognitively engaging adult learners. Fortunately, the definitive results of the needs assessments provided the parameters around which the curriculum could be organized.

Despite the notion that training curricula for caregiving already existed, the needs assessments clearly established a requirement for Alzheimer-specific caregiver training. The reliability of this need was definitely established by asking the same question, in a different manner, at two points in the questionnaires. Responses consistently and unequivocally showed that caregiver training was important and needed.

The questionnaire results also showed that training should be conducted in smaller time segments, with the majority of respondents choosing 2-3 hours or less of training delivered at a time. Additionally, the questionnaire results showed that the curriculum should be geared to an academic level of no greater than the 11th or 12th grade and probably lower. Caregivers in New Brunswick tend to include a large cohort of caregivers who are between 30 and 50 years old, with a substantial number (37%) over 50 years of age.

From an educator's point of view, the shortest time frames (one hour or less) do not necessarily deliver the best quality of training. Therefore, I decided that the curriculum should be designed in short modules (two to three hours), within which there would also be optional activities that could make the meeting time shorter, if necessary. Less significant activities could be eliminated if time commitments were critical.

I paid careful attention to the language that I used throughout the modules, not only in the information that I was asking facilitators to communicate to the learners, but also in the handouts for learner use. The choice of sentence structure and word use needed to be typified by easy understanding, brevity and conciseness, and to never be condescending.

From the needs assessment results on age, gender, and level of education, I was also aware that many caregivers are non-traditional learners. That is, the potential participants would have been away from an academic environment for a long time, had never aspired to high academic achievement levels, were working in a language that was not their mother tongue, and/or were apprehensive and doubtful about the benefits of classroom learning. To address such issues within the curriculum, I attempted to minimize lecturing and text book reading and maximize active learner participation through small group work.

The New Brunswick needs assessment indicated that the majority of caregivers had five or more years of experience. The curriculum attempts to draw on the practical skills and pre-existing knowledge that was already working successfully for the participants, by accessing real situations and people. This approach has the additional benefit of acknowledging and respecting the learners' personal experience and practical knowledge.

I was concerned that learning that was acquired with each module would not be lost as more material was presented with each new module. To that end, I created a bridging piece that carried over personal reflections from the previous week to group discussion in the next session. I also tried to incorporate many newly-acquired skills into each new module's sessions. For this reason, communication skills learned in the first module would augment learning in subsequent modules. This would, in turn, have an impact on the participants' ability to deal with stress and successfully interact with families.

Nearly one-third of respondents to the New Brunswick needs assessment indicated that the total time devoted to Alzheimer's training should be maximized at 12 hours, although a substantial number thought that it should continue for up to 18 hours. In order to satisfy basic training requirements, I decided to limit the modules to four segments, that would run for two to three hours. An additional module dealing with challenging behaviours could be added, as caregivers became more familiar with using their newly-recognized skills with their residents.

I suspected that when I created the needs assessment questionnaire and conducted the focus groups, I would begin to see content areas identified that needed to be included. Despite requesting preferences in questionnaires and asking for desired content areas in numerous focus groups, little consensus emerged as to relative importance. Every area seemed important. The content areas suggested as possible topics in the survey results received nearly equal distribution; however, I was not able to address all these content areas, principally because of time constraints.

As suggested earlier, content areas that were not addressed in these modules could be dealt with by adding a second round of training. Such training could more fully address the complicated tasks of daily living, such as bathing; challenging behaviours, such as sexual advances; and medication problems, including problems of drug toxicity and over medication.

I decided to limit the caregiver group size to approximately eight participants.This number of learners is not intimidating and allows a degree of safety in experimenting with new learning. Ideally, I wanted the participants to come from different facilities to maximize networking and idea exchanges. However, drawing learners from different shifts within the institution would also be an option.

Given the parameters described above, I struggled with making the learning fun, original, appropriate, logical, and cumulative. I knew that what I was not creating was just as important as what I was creating. I tried to use the facilitator as a guide, rather than a knowledge expert. I wanted, in the original teaching application, the participants to provide the major sources of expertise. I did not realize when I started just how difficult it would be to make something simple.

Chapter Four outlines the validation procedure and the changes that were made in the curriculum.

Chapter Four

Validation

4.1 Introduction

I created a validation questionnaire to be used by three validators whose names were unknown to me at that time. The purpose of the validation was to do a comprehensive assessment of the curriculum in terms of the appropriateness of content, support materials, teaching methods, and learning activities. The questionnaire (see Appendix B) allowed reviewers to rate items along a continuum of given responses, or to provide open-ended comments. The validation included sections for general impressions of the entire document and module-specific comments.

The three validators were chosen for their knowledge about Alzheimer's Disease, for their experience in developing educational programs for adult learners, and for their understanding of the issues related to long term care: The validators selected by my thesis supervisor were:

- Mary Dupuis, Professor of Nursing, University of New Brunswick
- Mary Lou Arsenault, adult educator and consultant to the Alzheimer Society of New Brunswick
- Rachel Clair, Executive Director, New Brunswick Association of Nursing Homes

All three validators received a complete curriculum package. This included facilitator and learner materials, teaching supplies such as overheads and handouts, video-tapes, dice, game pieces and a game board. Included in each curriculum package was the validation questionnaire. Each reviewer completed the questionnaire and returned it to Professor MacKeracher who reviewed the results and forwarded them to me with her comments.

Many of the validators' comments were based on differences of opinion about my choice of activities. My supervisor and I agreed that many of the alterantives suggested by the validators were equally as plausible and useful as the choices I had made. I assumed that if the alternatives proposed were equally good, I could use my original design and test it out at a later time. After the testing, I could then reconsider my choice.

I reviewed and organized the validators' comments and then decided which points needed to be addressed and which suggestions needed to be incorporated in the revised curriculum. The revised curriculum is provided as Appendix F. Once the curriculum has been tested all the concerns described in this chapter will be revisited.

The major sections in this chapter address the assessment of the individual modules and the general overall impressions of the validators. In each section, the concerns are first listed and then addressed individually. In some cases, my comments address several concerns taken together.

4.2 Module One

The following concerns were raised by the validators:

1. Module One should occur after Module Two.
2. There should be a brief introductory overview of communication theory.
3. There should be a revision of semantics so that communication is better described as a shared rather than solitary practice.
4. Revision of Overhead 1.3 to separate resident from caregiver actions
5. Revision of Handout 1.2 to address individual needs and abilities.
6. Revision of visualization exercise in order to address a wider audience.
7. Clarification of "Getting It Right" brainstorming discussion.
8. Revision of "Doing It Right" role-play time allotment to give adequate time for preparation and discussion.
9. Revision of "Doing It Right" role play group numbers to address performance anxiety.
10. Revision of goals from topics to be discussed.

I took considerable time to respond to the first concern -- that Module One should occur after Module Two. I recognize that the validators' concern was the provision of a safe learning environment and that such an environment could be created more easily by easing learners into the process by starting with Module Two. While such an approach might be more commonplace, I think that it disregards several other concerns -- that the use of learner time and institutional resources is important; that the major objective of the curriculum is to support experiential learning; and that the majority of learners are assumed to be somewhat experienced in the provision of care for patients with Alzheimer's Disease. I also think that the choice of the beginning module is a personal as well as professional choice. Therefore, the revised curriculum retains the original order of the modules. Once the curriculum has been tested, this concern will be revisited.

Other reasons for making the decision to retain the order of the modules are:

- I was concerned that some learners might have out-of-date learning skills, special learning needs, or poor academic backgrounds. I wanted to begin the curriculum with a topic which was familiar to the learners and which they could discuss on an equal footing with other learners and on the basis of their personal experience. I wanted them to have concrete subject matter to talk about when they first came together as a learning group.
- In addition to beginning with familiar content, the learning activities begin by having the learners working in pairs to reduce the possible distress of talking in the larger group.
- On the basis of my research and experience with caregivers, the fundamental and most important skill they can learn or improve upon is communication. They need to understand the importance of communicating skills, particularly in relation to those who have Alzheimer's Disease. I believe that beginning the

learning program with practical skills and knowledge that caregivers use often in their work life is more useful than beginning with academic knowledge.

- The learners need to become aware of the many communicating skills they already possess to effectively deal with many problem behaviours and of the skills in which they need improvement.
- Learning to communicate effectively with each other is as important for caregivers as learning to communicate with those who have Alzheimer's Disease.
- The goal of Module One is to help learners develop communicating skills early in the process so that these skills can be used in later modules. I also wanted the learners to develop new skills and knowledge which could be immediately tested in the workplace.
- If communicating skills are improved early in the learning program, the occurrence of incidents of severe resident behaviours may well decline in both frequency and severity.

The second concern -- the need for a brief introductory overview of communication theory -- addresses the issue of the starting point and order of learning activities to reflect the experiential learning cycle described by Kolb (1993). MacKeracher (1996) points out that facilitators tend to begin teaching activities with the experiential learning phase which most closely reflects their own learning style. Beginning with academic knowledge reflects an assimilator learning style; since my learning style is that of an accommodator, I prefer to begin with a more active, experiential activity. The choice of the beginning activity is another matter of personal choice. Based on my experience of working with caregivers, I think that they are more likely to use the converger, accommodator or diverger learning styles which suggest that beginning with an experiential activity is more suitable for them than beginning with an academic activity.

Concerns 3 and 4 -- to better describe communication as a shared rather than a solitary practice and to separate resident and caregiver actions -- seem contradictory. The overhead was prepared on the basis of the needs of both groups. Instructions to the facilitator have been expanded to include this point.

Concern 5 -- that Handout 1.2 should address individual needs and abilities -- is similar. I had assumed that Handout 1.2 did address individual needs. Again, instructions for the facilitator have been expanded to include this point.

Concern 6 -- that the visualization activity address a wider audience -- seems inappropriate since this program was designed to meet the needs of caregivers and the visualization activity addresses these needs rather than those of others who might work in other kinds of residential facilities. The design of any activity will always meet the needs of some groups more than other groups. The role of the visualization exercise is to momentarily induce a state of anxiety and agitation that often occurs in person with

Alzheimer's Disease. I believe that creating a benign environment would undermine the usefulness of the activity. The facilitator has been instructed to ensure that the debriefing that follows the visualization activity defuses any personal risk or anxiety that may be incurred as a result of the activity.

Concern 7 -- clarifying the instructions for the brainstorming activity associated with "Getting it Right" -- has led me to add the following instructions to more adequately address the issues that are not covered on the learners' lists but are covered in the handout and vice versa.

-- If participants suggest a point that is not on **Handout 1.2 Tips for Communicating with a Person who has Alzheimer's Disease,** the facilitator will take the time to acknowledge it and ask the participants to explain.

-- To ensure comprehension, as the list is being read, ask for examples if appropriate.

Concern 8 -- increasing the time allotment for the "Doing It Right" role-play -- is accepted and the time has been increased from 15 minutes to 30 minutes.

Concern 9 -- addressing performance anxiety in the "Doing it Right" role play -- is also accepted. The instructions to the facilitators include an option to form larger groups.

Concern 10 -- the term "goals" to be changed to "discussion topics" -- is accepted. The term has been changed in this and the other three modules.

4.3 Module Two

The following concerns were raised by the validators:

1. The content of the module needs to be expanded to include:
    - the prevalence of Alzheimer's Disease and why this is such an important issue for the health care system
    - the disease process according to stages and associated losses
    - the normal course of the disease
    - other types of dementia
    - major risk factors
    - current drug treatments
    - differential diagnosing
    - commonly encountered challenging behaviours (such as aggression and combativeness) that are most stressful to long term care staff
2. Process difficulties of having two presentations occurring at the same time
3. Concern voiced about the use of a Diagnostic Cognitive Test
4. Concerns about clue wording and the relative usefulness of a crossword puzzle for caregiver learners with limited knowledge of Alzheimer's Disease.
5. Difference of opinion over choice of skill in "Making Connections".
6. Encourage the use of videotapes.

While I agree with the sentiment expressed in the first concern -- that the content of the module needs to be expanded -- I have chosen to not include such an expansion in the curriculum for the following reasons:

- The overall goal of the learning program is to provide highly experiential and learner-centred activities. The content of Module Two, therefore, needs to focus on information that is directly related to the learners' roles as caregivers. The suggested additions to the content seem to be less practical and more academic in nature.
- With limited time and administrative budget constraints, the ideal of fully addressing information about Alzheimer's Disease must be superceded by the necessity to be realistic. Some learning topics had to be sacrificed.
- The topics were chosen to portray a basic understanding of the disease so that the challenges to learning would not be unrealistic to the practical needs of the learners.

The second concern -- that there may be processing difficulties of having two presentations occurring at the same time -- was considered carefully. This activity is meant to be executed exactly as written; that is, two group presentation are occurring simultaneously. This experiential activity is meant to simulate the reality of residents with Alzheimer's Disease who are trying to cope with compromised physical and cognitive deficits and often with two or more activities occurring simultaneously in their daily life. Who knows what 'other' voices those with dementia hear? Residents who live on wards must often cope with activities which may be separated visually, but not auditorally, by a fabric curtain. In dining rooms and activity areas they are often overwhelmed with multiple voices, noise and confusion over which they have little control. I wanted this activity to capture some of those difficulties even if it led to a 'messy' activity. This point has been included in the instructions to the facilitator.

The third concern involved the use of a Diagnostic Cognitive Test as a learning activity. I acknowledge that Folstein's Mini-Mental status test is the test most often used in the clinical diagnosis of dementia. The instructions clearly state that this test is **similar to** other cognitive tests used by physicians to help make a diagnosis of Alzheimer's Disease. Nevertheless, the point of this activity, as outlined in the Facilitator Notes, was that it was meant to be used as an experiential activity to simulate what a cognitive testing procedure can be like from the point of view of those with Alzheimer's Disease. In order to address the reviewer's concern that the diagnostic process is complex and comprehensive, as indeed it is, I have included a facilitator reference note that outlines other tests that are often used in the diagnostic process.

Concern 4 -- about clue wording and the relative usefulness of a crossword puzzle for caregiver learners with limited knowledge of Alzheimer's Disease. When the crossword puzzle was developed, careful attention was paid to word usage, the general population's knowledge of the disease, and alternative teaching strategies that would capture the abilities and interests of the learners. When the puzzle is completed, there is only one word that would not be part of lay person's knowledge. The aim of this activity is to foster learner activity through thinking about the causes of the disease and peer discussion. A lecture by the facilitator might be used but reflects a less active and less learner-centred teaching method. In order to address specific concerns with the crossword clues, the following changes have been made:

- Horizontal 3. Wording is changed from "Having Alzheimer's Disease is a m_____ challenge." to "Having Alzheimer's Disease is a m_____ and physical challenge."
- Horizontal 4. Wording is changed from "Alzheimer's Disease can only be definitely proved with an _______." to "Alzheimer's Disease can now be diagnosed with up to 95% accuracy. Formerly, it could only be definitively diagnosed by an ______ (dissection and examination after death)."
- Horizontal 10. Wording is changed from "Some say that the opposite of bacteria might cause Alzheimer's Disease" to "Some say that a v____ may cause Alzheimer's Disease."
- Vertical 4. Wording is changed from " Some say that a deep sadness late in life can trigger Alzheimer's Disease." to "A deep sadness, described as ________, frequently accompanies Alzheimer's Disease in its early stages."

Concern 5 is a difference of opinion over choice of skill in "Making Connections". In the handout "Making Connections" my aim was to make caregivers aware of a number of possibilities that might interfere with a resident completing a relatively simply skill, such as drying dishes. Residents will have difficulty with complex or new tasks, as do many of the general population. Caregivers often have difficulty with understanding residents who remember how to do a simple task one day and not the next. Those with Alzheimer's Disease often forget or remember only pieces of the simplest of skills. In designing the handout, the specific skill is irrelevant; however the physical, cognitive, and emotional processes of the resident with Alzheimer's Disease are not. The purpose of the activity is to make caregivers aware that what outwardly appears simple to them may not be so to those with Alzheimer's Disease.

Concern 6 -- Encourages the use of video-tapes. A number of videotapes about Alzheimer's Disease are available. While videotapes are easy to use, they call for little learner activity. I believe that in terms of applying the information learned in this module to a work situation, a videotape would have limited usefulness.

4.4 Module Three

The following concerns were raised by the validators:

1. Content missing about non-work related stress and its impact on caregiver behaviour in the workplace.
2. Content missing in sections on "Knowing what stress is."
3. Use of personal pronouns problematic
4. Relaxation exercise tends to be over-used.

5. Suggestion that aggressive behaviour in residents is a more important topic than methods to deal with stress.

The first two concerns -- about missing content -- were considered carefully. I agree that all of these issues are extremely important. In view of general caregiver profiles, stress from personal life can play a large role in the kind and quality of care that a caregiver is able to give those with dementia. With that realization in mind, and a limited time frame within which to deliver this module, I struggled with what information and which learning events would most benefit caregivers. I chose to reduce the topic of stress to its most basic tenets and promote learning activities that would have the greatest impact on the participants. According to adult learning principles, those learning activities would need to have a relational, interactive component. The activities would have to build upon their earlier experiences, be practical, relevant, and fun. I believe the learners would gain more from the planned activities than from what I sacrificed in theory.

The third concern -- over the use of personal pronouns in the Sources of Stress Activity -- is accepted. I agree that in this activity participants should not use personal pronouns. References to personal pronouns has been changed.

The fourth concern -- about the over-utilization of the relaxation activity was not accepted. Had I been writing curriculum for those with educational backgrounds like myself, I would probably agree that a relaxation exercise like this might be over utilized.

Considering the academic histories and life experiences of the caregiving population in general, I do not believe this to be the case. I doubt that these individuals would have ever had the opportunity to learn any relaxation techniques. In my opinion, the least beneficial teaching method for caregivers, considering the topic, would be a lecture on stress theory and little or no time to practice relaxation techniques or to discuss alternatives to stress relief with peers.

The fifth concern -- that aggressive behaviour in residents is a more important topic than methods to cope with stress -- was given careful consideration. One validator stated that most staff stress comes from work load and patient acuity, not from resident behaviours, although difficult behaviours are disturbing to the caregivers. I agree, but I do not see these as either/or issues, because both topics are important. Those who suffer from high levels of negative stress are less able to attend to the needs of others. Their personal needs are so great that their ability to deliver a high quality of care to someone else, let alone someone with impaired cognitive skills, is diminished. It is apparent from this that there is a greater imperative to deliver a module on the stress of caregiving, than a module on aggressive behaviour.

If I was going to develop a second curriculum to follow this one, I would include a module on challenging behaviours. It is my hope that caregivers who learn from this curriculum will demonstrate improved communication techniques, greater knowledge about the disease, have a better relationship with families and exhibit more capable care potential, because of adequate stress relief. In consequence, I think that the incidence and severity of challenging behaviours would decrease, thereby decreasing the imperative for learning to 'manage' resident behaviour.

4.5 Module Four

The following points were raised by the reviewers:

1. Missing program summary wrap-up and participant evaluation of program
2. Missing explicit recognition of previous experience of family members coping with Alzheimer's Disease and a loved one at home and that family caregivers remain caregivers after a loved one has been institutionalized.
3. Concern over incorrect use of term "Director of Nurses".
4. Inappropriateness of the board game as a learning tool and suggestion that case studies be used in place of the game.
5. Suggestion that family members be given a list of questions that will be asked ahead of time.
6. Concern over phrase 'dealing' with families.
7. Concern over quality of videotape.

Each of the points will be addressed in the following sub-sections:

4.5.1 Program wrap-up and participant evaluation of program.

I agree that time should be given for the program summary and evaluation. I have added 30 minutes to the fourth module which will include the following written evaluative activity and large group discussion. The summary and evaluation will directly follow the reflective activity.

Pride in Alzheimer's Care Evaluation **30 minutes**

1. During this program, I learned the fundamental components of giving care to those with Alzheimer's Disease.

   Strongly Agree Agree Disagree Strongly Disagree

2. During this program, I learned how to communicate better with those whom I care for who have Alzheimer's Disease.

   Strongly Agree Agree Disagree Strongly Disagree

3. During this program, I learned about Alzheimer's Disease and how it affects those with the disease.

   Strongly Agree Agree Disagree Strongly Disagree

4. During this program, I learned about several methods to reduce stress.

   Strongly Agree Agree Disagree Strongly Disagree

5. During this program, I learned about the impact of Alzheimer's Disease on families.

   Strongly Agree Agree Disagree Strongly Disagree

6. I found the content material in this program excellent.

   Strongly Agree Agree Disagree Strongly Disagree

7. The information that I learned in this program will be useful to me at work.

Strongly Agree Agree Disagree Strongly Disagree

8. The learning activities used in this program added to my understanding of the content materials.

Strongly Agree Agree Disagree Strongly Disagree

9. The facilitator was able to explain the material clearly.

Strongly Agree Agree Disagree Strongly Disagree

10. The facilitator used teaching strategies that helped me to learn

Strongly Agree Agree Disagree Strongly Disagree

11. This program has changed the way that I give care to those with Alzheimer's Disease

Strongly Agree Agree Disagree Strongly Disagree

12. I would recommend this program to other caregivers.

Strongly Agree Agree Disagree Strongly Disagree

Wrap-up Discussion

Preparation:

- None

Facilitator Notes:

This activity is meant to help participants think about the whole program; about what aspects have been most meaningful to them and what aspects could be improved; and to bring closure to the time spent together.

Method:

- Find a seat that places you amongst the participants or closes a U-shaped seating arrangement.
- Inform the participants that this activity will bring an end to your time together and that you are looking forward to sharing their final thoughts.
- Tell them that you would like them to take a few moments and reflect on all four sessions. Tell them that you would like to know just two things. Ask them to think about the first question: If you could change anything about the program in general, what would it be?
- When they have had a few moments to reflect, tell them that you would like to go around the room and give everyone an opportunity to speak.
- After everyone who wishes to has spoken, ask them to think about the second question: How will you deliver care to residents that is different now than before you had this program?
- After giving the participants a chance to reflect, ask each in turn for their comments.
- Ask if anyone has anything more that they would like to say.
- Thank them very much for coming.

4.5.2 Previous experience of family members in coping with Alzheimer's

This reviewer makes a very good point and I agree that the issue of the family's previous caregiving experience and ongoing caregiving concerns despite a loved one's institutionalization has not been stated explicitly. In order to rectify this oversight, I have included the following mini-lecture that should be given to the participants prior to the visit of guest family(ies).

Mini-lecture **10 minutes**

Preparation

- **Working with Families (Overhead 4.2)**
- Facilitator review of mini-lecture notes: The Role of the Family in Alzheimer's Care

Facilitator Notes:

This mini-lecture will serve two purposes. It will emphasize the roles that family members have played in the care of their loved ones and will serve as an introduction to the family visit that will occur just after this mini-lecture.

Method:

- Use the facilitator notes **"The Role of the Family in Alzheimer's Care"** to develop your mini-lecture. Do not read the notes - use them to develop your talk for the learners.
- Put up **Working with Families (Overhead 4.2)** Present the facts simply. Do not use complicated words or sentence structure. Refer to the

overhead as you speak. It is your prompt for the progression of the mini-lecture.

- Tell the participants that they may take notes.

Facilitator Preamble Notes:

The Role of the Family in Alzheimer's Care

The Caregiver

Alzheimer's Disease not only affects the person with the disease, but their entire family. Those who work in the Alzheimer's field call family caregivers 'the second patient.' This is because the care that they provide to their loved one is unending, consuming, stressful, exhaustive, and often leads to a quick decline in their own health. Alzheimer's Disease also affects the strengths and weaknesses of existing family relationships. Throughout the course of the disease, families are forced to cope with an unending range of conflicting and difficult emotions.

Caregivers cope with feelings of anger as the disease their loved one is experiencing places increasing demands upon them. Often those with Alzheimer's Disease can appear deceptively well, yet still make difficult and unrealistic demands upon the caregivers. These unreasonable demands often cause anger and guilt. Feelings of guilt are compounded by feelings of being overburdened with care concerns. More guilt may be added if other family and friendship roles must be neglected.

Caregivers are often burdened with feelings of embarrassment because of the unusual behaviours of their loved one. They may feel that having a family member with a mental health disease means the family has been disgraced.

Caregivers suffer from frustration at being able to do so little, about having so little control over their own lives, and about the indecision that often accompanies the decisions they must make about the future. Others feel abandoned as friends and family members turn away. Many caregivers become depressed, isolated, and unsure about whom to turn to. Caregivers grieve for the loss of their normal way of living, and of the companionship of the person with the disease. This grieving is confused by the fact that the person is still alive in body but gradually slipping away in person. Adding to this confusion is the fact that on some days, their loved one behaves normally. Such days can cause caregivers to wonder if there is a problem, if it will go away, or if it is they themselves who are the problem.

Once the disease has progressed to the point where the caregiver can no longer care for their loved one at home, they experience tremendous guilt about placement in long term care. Their stress may increase if they feel guilty about having ‘given up’ on their loved one and if they feel they have failed as a caregiver. Family members and friends may not understand that the caregiver’s home life has deteriorated, thereby adding to the caregiver’s unhappiness.

Family caregivers whose loved ones reside in long term care do not stop being caregivers. Some caregivers ‘double-up’ their caregiving role once the loved one has been institutionalized, in order to placate their own feelings of guilt. Many caregivers experience difficulty in letting go of their roles or their relationships.

The Family

Three types of conflicts generally exist within families who struggle with Alzheimer's Disease. First, some family members may disagree over the severity of the disease and the course of action to be taken. Second, they may disagree over the roles of the main caregiver(s) and other family members. Some family members disappear, others fulfill caregiving roles, while still others choose to help in less direct ways than hands-on caregiving. Third, other difficulties arise when the main caregiver becomes overburdened and resentful of the enormity of the task. Roles shift once again as the disease progresses, and placement in long term care becomes an option.

4.5.3 Incorrect use of the term Director of Nurses

I agree that 'Director of Nurses' is not correct and it has been changed in all cases to 'Director of Nursing'.

4.5.4 Appropriateness of a board game as a learning tool.

While I do not agree that the board game is inappropriate, I have included a case study as an option.

Option 2: Case Study **20 minutes**

Maurice Cameron, 75 years old, was admitted to the local nursing home one year ago. He was an amiable, pleasant man diagnosed with Alzheimer's

Disease. At the time of admission, he received only the drug Arisept for the disease, which he had been accepting very well. He had lived in the local area and his wife and one of his two daughters lived nearby.

His wife, Eva, visited faithfully every day and stayed several hours. She was a sweet old lady who had nothing but kind things to say to the staff. At times, Maurice was verbally abusive to his wife. If she did not arrive at the appointed hour each day, he would become agitated and bother the staff with constant demands, asking where his wife was, and why wouldn't they let him phone her. When they gave in and phoned his wife so that he could talk to her, he would become very abusive to his wife. Some of these calls were intercepted by the staff and they found his wife crying on the telephone.

After several months, the staff noticed that Maurice seemed considerably worse. He made less sense when he talked, started crying more often, and would become much more agitated and aggressive during the night. The staff tried medicating him at night. However, this had no effect on him during the night and he became more confused during the day. One cold winter night, he was found at the entrance to the home trying to get back in. He had obviously escaped through a coded door and had found his way back to the entrance. No one had noticed his absence. When asked why he had left, he replied that he had wanted to check his bird feeder outside his window. After that incident, he was labelled an "escape risk" and was constantly watched by the staff.

The staff noticed that his wife, Eva, started to deteriorate as well. When she visited, she did not look well, and during one visit, she collapsed. An ambulance was called and she was taken to the hospital. The second day after this incident, Eva arrived back at the nursing home to resume visiting her husband on a daily basis. Each time she visited, she would ask the staff how her husband had been. The staff would truthfully tell her what events had taken place since her last visit. She seemed to take the news well each time when it was given, although after several weeks she began to look terrible, started losing weight, and often cried as she was leaving the facility.

Maurice's children visited irregularly. His elder daughter was surly and complained often to the staff about the poor quality of care that her father was receiving. The other daughter lived so far away that she phoned more than she visited. When she called, she often asked how her father was. The staff reported for a long time that all was well. More recently, when Maurice had become an escape risk and a problem for the staff, they were less forthcoming. Finally, the administration and staff wanted him removed from the facility to a locked unit at another facility. The family did not want him moved and did not want him given night medication.

Questions for discussion:

What role does each member of Maurice's family play?

What did the staff do well in this case?

What errors did the staff make with Maurice's care, if any?

What could the staff have done differently?

What would you have done if Maurice were part of your work assignment during the day? During the night?

Preparation:

- Sufficient copies of the Case Study and accompanying questions.

Facilitator Notes:

The aim of this activity is for participants to become aware of the role of family members of those they care for and how those roles can impact care. The questions are meant to create discussion about what occurred in the case, what role caregivers played, and what role they should or should not have played. The questions also ask the participants to put themselves into the situation and reflect what they might have done if they were the caregivers in question.

It is important for facilitators to understand that their role in this activity is to guide the participants' exploration of the questions. It is inappropriate for facilitators to assign guilt, or to assume there is a correct answer. This case study explores the conundrums that many caregivers face in the delivery of care. It serves to illustrate that often care concerns have no easy answers.

Method:

- Pass out the case study and questions to the participants.
- ▸ Ask for a participant to read the case study or read it out loud yourself.
- ▸ Ask participants to find a partner. When they have found a partner, ask them to read the questions together and discuss them.

- Give the learners 5 minutes to discuss their answers.
- Open the discussion to the floor and lead the discussion of the questions, ensuring that as many participants as possible have the opportunity to speak.
- Give the group 10 minutes to explore their answers. Thank them for their answers and have them move on to the final activity.

4.5.5 Prepare family members ahead of time.

This is a very good idea and the following list of possible questions will be included in the curriculum to be given to families before attending the group session:

Questions for Visiting Family

Thank you so much for agreeing to attend our *Pride in Alzheimer's Care* Course. The following is a list of possible questions that may be asked of you when you visit our training program. If you are uncomfortable about answering any of the following questions, please let me know at the following number (___-____) and I will ensure that the question(s) will not be asked.

1. Would you tell us about yourself?
2. Would you tell us about your loved one, the member of your family who has Alzheimer's Disease?
3. Would you tell us how Alzheimer's Disease has affected your family?

4. Would you tell us how your loved one came to be placed in long term care?
5. If you would not mind, would you tell us how you felt about placing your loved one in long term care?
6. Can you tell us what you like best about where your loved one now resides?
7. Is there some element of care that you wish you could change at the facility where your loved one resides?
8. What is one thing that you wish caregivers knew about your loved one?
9. If you could give one piece of advice to those who care for your loved one, what would it be?

4.5.6 Concern over phrase 'dealing with families.'

I agree that the word usage is inappropriate and all references have been changed to more appropriate wording.

4.5.7 Concern over quality of video-tape.

I agree that the quality of the video-tape was not what I had hoped for. I searched extensively to find a videotape that would portray the feelings of the families who live with loved ones who have Alzheimer's Disease. Unfortunately, the video-tape which I selected for this module was not of the best quality and therefore the dubbed version of my original, despite my best attempts, was not much better. For the final version of the curriculum, I will attempt to obtain a better copy of the tape and will provide a list of other videotape resources which could be used by the facilitator.

4.6 Summary

The changes outlined in Chapter Four have been incorporated in the curriculum which appears as Appendix F. Once the curriculum has been tested, the modules will again be reviewed and revised as necessary. Chapter Five provides a summary of the project and recommendations for further activities.

Chapter Five

Conclusion

5.1 Introduction

Delivering good quality care to those who have Alzheimer's Disease and related dementia is a difficult task. It requires tremendous amounts of caregiver patience, knowledge, communication skill, ingenuity, and self-knowledge. Recognizing the important skills to be a good caregiver is easy; on the other hand, developing a curriculum that teaches these skills and leads to having those skills practiced by adult learners in the workplace, is quite a different matter.

In this chapter, I summarize the process I undertook to create a training curriculum for those who work in long term care, and who provide a kind of care that permits those who live with Alzheimer's Disease to enjoy the highest quality of life that their disease progression allows. I then relate what I learned about doing this kind of research and the process of curriculum validation that followed. Finally, I describe my plans for the future of the curriculum.

5.2 Process Summary

Writing curriculum for those with Alzheimer's Disease demands knowledge in several content areas. For this endeavour I needed expertise in several large fields of knowledge: the nature of Alzheimer's Disease, the nature of care provided to persons with Alzheimer's Disease, and adult learning principles. First, I researched Alzheimer's Disease and related dementia, primarily in areas that related to the impact of the disease upon the individual and caregivers (including families). Throughout this study, I became increasingly aware of the necessity to differentiate between various philosophies of providing care and the impact of these different approaches upon training caregivers. Then, I used my Adult Education studies to target the needs of the caregiver learner, to assess current training materials, and to apply adult learning principles to the development of an original training curriculum.

In order to make sure that I was addressing the actual needs of caregivers, I conducted a survey of home administrators in New Brunswick. I augmented this data with information gathered as part of a project I conducted with the Alzheimer's Association at several sites in the U.S. The results of this information gathering process gave me the parameters around which the content for the curriculum was created.

I reviewed available curricula designed to train caregivers about working with persons with Alzheimer's disease and related dementia. Eleven curricula were selected and assessed in terms of criteria related to perspectives of the caregivers, the facilitator, and the organizations sponsoring the training.

I developed a curriculum consisting of four three-hour modules focusing on: communication skills, knowledge of Alzheimer's Disease, stress, and working with families. The curriculum was validated by three knowledgeable New Brunswickers and revised.

5.3 Recommendations to Those who would Develop Curricula

Writing curriculum is difficult, time-consuming work. It requires a vast accumulation of knowledge and endless research. The field of dementia training is relatively young and training materials are difficult to find, despite anecdotal evidence to the contrary. In my search for curricula, I was sure that there was always a better curriculum 'out there' and that I just had not found it yet. After years of searching, I had not found the perfect materials, and in the interim, other materials were created and so the search for the ultimate curriculum never ended. Also, research in Alzheimer's Disease and dementia is rapidly developing. Medical breakthroughs made some of the curriculum material redundant practically before it was written, let alone validated. There comes a point when the search must end and the writing must begin. Students who plan to write a curriculum would do well to understand from the beginning that the perfect curriculum is non-existent.

Dwindling budgets make administrators in long term care facilities less and less concerned with providing quality training for staff members who may leave after a short time. From an administrative perspective, training should take the least possible time and cost the least amount of money. Adult educators know that teaching methods, like reflective practice and group discussion which take time and offer few easily identifiable evaluation measures for administrators, are often the most productive part of a caregiver's learning process. Since my goal was to produce a curriculum that would be topical, practical and useful, I often found myself caught between the ethical extremes of writing good learning materials from an adult education perspective, and squeezing the materials into the tightest possible parameters of minute-time chunks and fewest dollars allocated by administrators. After all, I often thought, what good are excellent materials if they are never used?

I have learned that curriculum writing is a task that is usually not an individual endeavour. The task, if done properly, is just too monumental. Having a team to work together on difficult areas would have made a tremendous difference. It is possible to be creative when working alone, but it is easier to be more creative when working with others. Access to university resources such as copiers, libraries, and collegial friendships would all have made the process easier and much more enjoyable.

Finally, any curriculum, in my opinion, should always be considered a `work in progress' that will continually be adapted and revised. As adult learning practice becomes more sophisticated, as dementia discoveries are made, and as changes in dementia care practice evolve, the need for amendments to any curriculum will, and indeed, should continue. No matter how good a curriculum is, it will always contain activities that do not create the learning environment the writer is expecting. There will always be contexts, learners, and facilitators for whom the curriculum will not be suitable. There will always be administrators who insist on minimal training and who allocate inadequate personnel or training dollars. There will always be learners who are anxious about learning or who believe they do not need more training. There will even be facilitators who have little understanding of adult learning principles and see little relevance in teaching and learning practices that differ from their own experiences.

5.4 Validation Recommendations

For those who have difficulty with others critiquing their work, the validation process can be hard to swallow and digest. When I developed the validation questionnaire, I thought that it should be a comprehensive review of each individual module. and of the curriculum as a whole. In retrospect, I expected to receive suggestions that would call for minor revisions but not suggestions that would require an almost complete revision and rethinking of some modules.

In writing a validation questionnaire, I would advise the author to know the people for whom it is being developed. I wrote the questionnaire without a conscious awareness of how the questions might be interpreted, or indeed, answered. I structured the questionnaire around responses that I might give to another in the same situation. Since I am the kind of teacher who uses positive reinforcement to guide learning, I expected to receive only positive feedback and was unprepared for some of the negative feedback I received.

I would also recommend, if possible, a validation procedure that occurs over a period of time. In my case, for instance, it would have been preferable to receive the validation one module at a time. I would have been much more prepared to change or adapt the modules one at a time.

5.5 Future Endeavours

5.5.1 Future Training

Since I work for the Alzheimer's Association, I will have the opportunity to test the curriculum as it is written. During the autumn of 2000, I will be offering *Pride in Alzheimer's Care* in the Williamsburg, Virginia, area. It will be offered free of charge (as are all programs administered by the Alzheimer's Association in the Hampton Roads Chapter) to a number of assisted and skilled living facilities. The numbers of participants will be limited to eight people, enrolled on a first come, first served basis. Although the details are not finalized, I expect to teach the program once a week for a period of four weeks. Participants can either volunteer for the program or be asked to attend by their facilities. I will be asking a colleague to attend to give feedback.

5.5.2 Revisions

At this point, I know that the curriculum will be more valuable and more widely used by facilities if the content of each module is limited to one (ideally from an administrator's perspective) to two hour time blocks. I intend to use the training experience as outlined above as a guide to determine what material can be eliminated in the module and what must remain to maintain the integrity of the content and meaningfulness to the learners.

5.5.3 Translation

I had originally intended to offer the curriculum in both French and English in New Brunswick. However, I have found that current computer translation software is not good enough to develop a translation of the program that will adequately address the needs of those who work in long term care in New Brunswick. If it is possible to find the necessary funding, I would be pleased to be able to have the curriculum available for the use of French-speaking caregivers.

5.5.4 Curriculum availability

The Alzheimer Society of New Brunswick and the New Brunswick Association of Nursing Homes were very helpful to me as I began my research in curriculum development at the University of New Brunswick. I intend to make the curriculum available for their use. I believe that the curriculum package will work most effectively if I can be involved in the initial training of potential facilitators.

5.6 Conclusion

As baby-boomers age, Alzheimer's Disease becomes more significant daily. This devastating disease which is quietly populating the halls and corridors of long term care facilities everywhere, is quickly becoming the disease of our time -- too huge to ignore. As the incidence of Alzheimer's Disease escalates, the need for training caregivers who can deliver compassionate dementia care is critical. Caregiving for those with dementia requires specialized training that incorporates understanding and respect for those with the disease and is based on the learning needs and special strengths of those who deliver the care. We need to train caregivers well; the care that is given may well be for us.

Bibliography

Alzheimer Society of Canada. (1996). *Care at home*. Toronto, ON: Author.

Alzheimer Society of Canada. (1997). *Alzheimer Disease: Care at home. Evaluation report*. Toronto, ON: Author.

Alzheimer's Disease and Related Disorders Association. (1991). *Just for the summer*. Chicago, IL: Author.

Alzheimer's Disease and Related Disorders Association. (1993). *Provider intensive workshop: Training for professional caregivers.* Chicago, IL: Author.

Alzheimer's Disease and Related Disorders Association. (1996). *Alzheimer's Disease fact sheet*. Chicago, IL: Author.

Alzheimer's Disease and Related Disorders Association. (1997). *Activity based Alzheimer care: Building a therapeutic program.* Chicago, IL: Author.

Andresen, G. (1995). *Caring for people with Alzheimer's Disease: A training manual for direct care providers.* Baltimore, MD: Health Professions Press.

Apps, J. (1991). *Mastering the teaching of adults.* Malabar, FL: Krieger Publishing.

Aronstein, Z., Olsen, R. & Schulman, E. (1996). The nursing assistants use of recreational interventions for behavioral management of residents with Alzheimer's Disease. *The American Journal of Alzheimer's Disease*, *May/June*, 26-31.

Austrom, M. (1996). Training staff to work in special care. In S. Hoffman, & M. Kaplan (Eds.), *Special care programs for people with dementia* (pp. 17-36). Baltimore, MD: Health Professions Press.

Barba, B., Ehrmann, I., Koff, T., Myers, L., Parker, L., & Scott, R. (1990). *Alzheimer's Disease: Pieces of the puzzle. A training program for direct service staff and family caregivers.* Phoenix, AZ: University of Arizona, Long-Term Care Gerontology Center.

Beatty, P., & Wolf, M. (1996). *Connecting with older adults: Educational responses and approaches.* Malabar, FL: Krieger Publishing.

Beck, C., Ortigara, A., Mercer, S., & Shue, V. (1999). Enabling and empowering certified nursing assistants for quality dementia care. *International Journal of Geriatric Psychiatry, 14*, 197-212.

Belenky, M., Clinchy, B., Goldberger, N., & Tarule, J. (1986). *Women's ways of knowing: The development of self, voice and mind.* New York: Basic Books Inc.

Bell, V., & Troxel, D. (1997). *The best friends approach to Alzheimer's care.* Baltimore, MD: Health Professions Press.

Bowlby, C. (1993). *Therapeutic activities with persons disabled by Alzheimer's Disease and related disorders.* Gaithersburg, MD: Aspen Publishers.

Boyd, E., & Fales, A. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology, 23*(2), 99-117.

Canadian Journal of Health and Aging, Policy Advisory Committee (1994). Patterns of caring for people with dementia in Canada, *Canadian Journal on Aging, 13*(4), 470-487.

Consult Services Incorporated (1993). *Keys to better care: Trainer's manual. A training program for nursing home staff caring for people with Alzheimer's Disease and related dementia.* Narbeth, PA: Author.

Dippel, R. & Hutton, J. (1996). *Caring for the Alzheimer's patient: A practical guide* (3rd ed.). Amherst, NY: Prometheus Books.

Elliott, G., Hunt, M., & Hutchison, K. (1996). *Facts on aging in Canada.* Hamilton, ON: McMaster University, Office on Gerontological Studies.

Fabiano, L. (1998). *The tactics of supportive therapy: A comprehensive intervention program for effective caring of the Alzheimer's victim* (2nd ed.). Seagrave, ON: FCS Press.

Fazio, S., Seman, D., & Stansell, J. (1999). *Rethinking Alzheimer's care.* Baltimore, MD: Health Professions Press.

Flett Consulting Group. (1992). *A study of care practices for persons with dementia in Ontario's homes for the aged: Special care units.* Toronto, ON: Author.

Foner, N. (1994). Nursing home aides: Saints or monsters? *The Gerontologist, 34* (2), 245-250.

Gauthier, S., Panisset, M., Nalbantoglu, J., & Poirier, J. (1997). Alzheimer's Disease: Current knowledge, management and research. *Canadian Medical Association, October*, 1047-1052.

Gilley, J., & Boughton. N. (1996). Stop managing, start coaching. *Soundview Executive Summaries, 18*(4), 1-8.

Grant, L., Kane, R., Potthoff, S., & Ryden, M. (1996). Staff training and turnover in Alzheimer special care units: Comparisons with non-special care units. *Geriatric Nursing, November/December*, 278-282.

Grinspoon, L. (1998). Alzheimer's Disease: The search for causes and treatments. *The Harvard Mental Health Letter, 15*(2), 16-19.

Gruetzner, H. (1992). *Alzheimer's: A caregiver's guide and sourcebook.* New York: John Wiley & Sons.

Gwyther, L. (1985). *Care of Alzheimer's patients.* Chicago, IL: American Health Care Association.

Gwyther, L., & Ballard, E. (1990). *Optimum care of the nursing home resident with Alzheimer's Disease*. Durham, NC: Duke University Medical Center.

Gwyther, L. & Rabins, P. (1996). Practical approaches for treating behavioral symptoms of people with mild to moderate Alzheimer's Disease. *Primary Psychiatry, December*, 27-39.

Hamdy, R., Turnbull, J., Norman, L. & Lancaster, M. (1990). *Alzheimer's Disease: A handbook for caregivers*. Baltimore, MD: C.V. Mosby.

Hanser. S. (1994). *Dementia in the long-term setting: Training for dignity.* San Francisco, CA: Alzheimer's Disease and Related Disorders Association, Greater San Francisco Bay Area Chapter.

Hays, A., & Dowling-Williams, T. (1997). Perceptions of job satisfaction in a long term care facility: A comparison between a dedicated Alzheimer's unit and non-Alzheimer's units. *American Journal of Alzheimer's Disease, January/February*, 35-39.

Heine, C. (1986). Burnout among nursing home personnel. *Journal of Gerontological Nursing, 12,* 14-18.

Hekelman, F., Segall, M., & Wykle, M. (1989). Developing a geriatric curriculum for home health aides: Providing care to Alzheimer's patients. *Educational Gerontology, 15*, 213-219.

Helm, B. & Wekstin, D. (1995). *For those who take care: An Alzheimer's Disease training program for nursing assistants*. Lexington, KY: University of Kentucky Press.

Johnson, L. (1994). *Creating caring environments for the person with dementia.* Victoria, BC: Psychogeriatric Consultation Outreach Service.

Kane, R., & Caplan, A. (1990). *Everyday ethics ... Resolving dilemmas in nursing home life.* New York: Springer Publishing.

Kaplan, M. (1998). Training staff in behavior management. In M. Kaplan & S. Hoffman (Eds.), *Behaviors in dementia: Best practices for successful management* (pp. 47-61). Baltimore, MD: Health Professions Press.

Khalsa, D., & Stauth, C. (1997). *Brain longevity: The breakthrough medical program that improves your mind and memory.* New York: Warner Books.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* London: The Open University Press.

Knowles, M. (1980). *The modern practice of adult education: From pedagogy to andragogy* (2nd ed.). New York: Cambridge.

Kolb, D. (1993). The process of experiential learning. In M. Thorpe, R. Edwards, & A. Hanson (Eds.), *Culture and processes of adult learning: A reader* (138-156). London: The Open University Press.

LeDuc, L. (1993). *Alzheimer's Disease in long term care facilities: A dicussion paper.* Toronto, ON: Alzheimer Society of Canada.

Maas, M., Buckwalter, K., Swanson, E., & Mobily, P. (1994). Training: Key to job satisfaction. *The Journal of Long-Term Care Administration, Spring*, 23-26.

Mace, N. (1996). Teaching the care of people with dementia: Can the newly-trained implement what they have learned? *American Journal of Alzheimer's Disease, January/February*, 32-34.

Mace, N., & Rabins, P. (1991). *The 36-hour day.* Baltimore, MD: The John Hopkins University Press.

MacKeracher. D. (1996). *Making sense of adult learning.* Toronto, ON: Culture Concepts.

McGillick, J. (1997). *Training the trainer: Building creative caregivers* (3rd ed.). St. Louis, MO: Alzheimer's Disease and Related Disorders Association, St. Louis Chapter.

Mercer. S., Heacock, P., & Beck, C. (1993). Nurses aides in nursing homes: Perceptions of training, work loads, racism and abuse issues. *Journal of Gerontological Social Work, 21*(2), 95 – 112.

Morrissett, I., Stevens, W.W. Jr., & Woodley, C. P. (1969). A model for analysing curriculum materials and classroom transactions. *Thirty-ninth Yearbook of the National Council for Social Studies* (pp.229-276). Washington, DC: National Council for Social Studies.

National Institute of Mental Health. (1994). *Alzheimer's Disease* (NIH No. 94-367). Baltimore, MD: Author.

National Institute of Mental Health. (1998). *Progress report on Alzheimer's Disease* (NIH No. 98-3616). Baltimore, MD: Author.

Nayak, V., & Tellis-Nayak, M. (1989). Quality of care and the burden of two cultures: When the world of the nurses's aide enters the world of the nursing home. *The Gerontologist, 29*(3), 307-313.

Patterson, C. (1998). *The recognition, assessment and management of dementia disorders: The 1990 Canadian Consensus Conference on Dementia.* Hamilton, ON: Health Sciences Corporation.

Popcorn, F. (1992). *The Popcorn report.* New York: HarperCollins.

Reisberg, B. (Ed.). (1983). *Alzheimer's Disease: The standard reference.* New York: The Free Press. <http://www.alzheimer.ca/alz/content/index-disease-eng.htm> (Accessed 3 February 2000).

Rogers, J. (1998). *Candle and darkness: Current research in Alzheimer's Disease.* Chicago, IL: Bonus Books.

Schiff, M. (1994). More than 'a better bird cage': Units for residents with dementia, *Long Term Care Monitor, 5*(2), 10-12.

Seman, D., & Stansell, J. (1995). *Activity programming for persons with dementia: A sourcebook.* Chicago, IL: Alzheimer's Disease and Related Disorders Association.

Small, G., Rabins, P., Barry, P., Buckholtz, N., DeKosky, S., Ferris, S., & Finkel, S. (1997). Diagnosis and treatment of Alzheimer's Disease and related disorders. *Journal of the American Medical Association, October 22-29*, 363-1371.

Svinicki, M., & Dixon, N. (1987). The Kolb model modified for classroom activities. *College Teaching, 35*(4), 32-54.

Sweetnam, J. (1999). *Alzheimer's Disease caregivers' training: Caregivers and administrators' perspectives.* Unpublished report available through the Alzheimer's Disease and Related Disorders Association, Chicago, IL.

Szwabo, P.A., & Stein, A.L. (1993). Professional caregiver stress in long term care. In P.A. Szwabo & G.T. Grossberg (Eds.), *Problem behaviors in long-term care. Recognition, diagnosis, and treatment.* New York: Springer Publishing.

Tavormina, C. (1999). Embracing the Eden Alternative in long-term care environments. *Geriatric Nursing, 20*(3), 158-161.

Tennessee Professional Development Website (2000). Curriculum mapping FAQ. Accessed April 28, 2000, at http://www.k-12.state.tn.us/tpd/emfaqanswer.htm

Teri, L., Baer, L., Orr, N., & Reifler, B. (1991). Training nursing home staff to work with Alzheimer's Disease patients. *Gerontology and Geriatrics Education, 11* (3), 77-83.

Thatcher, D. (1990). Promoting learning through games and simulations. *Simulation & Gaming, September*, 263-273.

Turner, C. (1996). XBS learns to grow. *Fast Company, October-November*, 113-122.

Volicer, L., Fabiszewski, K., Rheaune, Y. & Lach, K. (1988). *Clinical management of Alzheimer's Disease.* Gaithersburg, MD: Aspen Publishers.

Whall, A., Black, M., Yankou, D., Groh, C., Kupferschmid, B., Foster, N. & Little, R. (1999). Nurse aides' identification of onset and level of agitation in late stage dementia patients. *American Journal of Alzheimer's Disease, 14*(4), 202-206.

World Health Organization. (1994). *Alzheimer's Disease: Help for caregivers* (WHO/MNH/MND/94.8). Geneva: Author.

Zemke, R. & Zemke, S. (1988). 30 things we know for sure about adult learning. *Training, July*, 57-61.

Appendices

Appendix A

Needs Assessment:

New Brunswick Association of Nursing Homes

The purpose of this study was to determine the needs for training in member homes in the New Brunswick Association of Nursing Homes. The questionnaire was mailed to 62 nursing homes; return rate was 100%. Except where indicated, the numerical values represent frequency counts.

Training for Caregivers of Alzheimer's Patients
La Formation Para-Professionelle pour la maladie d'Alzheimer
(TOTAL: 62 homes in NB - 41 English, 21 Français)

Q.1 Do members of your staff require specific training for working with patients with Alzheimer's Disease and other related dementias? Avez-vous besoin d'une éducation specialisé pour votre personnel qui prend soin des patients souffrant de la maladie d'Alzheimer?	**Yes/Qui**	**No/Non**	**Total**
	56	6	62

Q.2 How would you prefer that your staff receive training? Avez-vous une préférence concernant la méthode de l'éducation?	**English**	**Français**	**Total**
• Self study at home // L'éducation par soi-même chez soi.	4	1	5
• 2-3 hour small group sessions in the evening // Une séance de 2-3 heures en petit groupe le soir.	5	7	12
• 2-3 hour small group sessions during the day // Une séance de 2-3 heures en petit groupe pendant la journée.	17	10	27
• Full day session on weekdays // Une journée complete pendant la semaine	10	3	13
• Full day session on weekend // Une journée complete pendant le fin de semaine	2	0	2
• Other (please specify) // Autres suggestions?	3	-	3

Q.3 At what academic level would the training be most appropriate? Quel niveau scolaire serait souhaitable pour cette formation?	English	Français	Total
• Grade 8 or below // Le 8iéme niveau ou moins	0	0	0
• Grade 9-10 // Entre 9-10iéme niveau	3	3	6
• Grade 11-12 // Entre 11-12iéme niveau	21	9	30
• Above Grade 12 // Plus que le 12iéme niveau	17	9	26

Q.4 What percentage of your staff is: Quel pourcentage de vos employés a:	English	Français	Total
• Under 30 years of age // Moins de 30 ans	2	3	8%
• 30-50 years of age // Entre 30 et 50 ans	24	10	55%
• Over 50 years of age // Plus de 50 ans	15	8	37%

Q.5 How many hours of training do you think your staff members need? Combien d'heures pensez-vous devrez être consacrés à l'éducation de la maladie d'Alzheimers?	English	Français	Total
• Less than six hours // Moins de six heures	6	4	10
• Between 6 and 12 hours // Entre 6 et 12 heures	16	12	28
• Between 12 and 18 hours // Entre 12 et 18 heures	13	5	18
• More than 18 hours // Plus de 18 heures	6	0	6

Q.6 Would you prefer training material to be provided in ... Préfériez-vous que la documentation soit écrite en ...	English	Français	Total
• English only // anglais	28	0	28
• French only // français	0	10	10
• Both English and French // tous les deux	13	11	24

Q.7 How many years of practical caregiving experience does your staff have? Combien d'années d'expérience vos aides soignantes ont-elles?	English	Français	Total
• Less than one year // Moins d'un an	0	0	0
• One to two years // Entre un et deux ans	3	0	3
• Three to four years // Entre trois et quatre ans	7	2	9
• Five years or more // Cinq ans ou plus	31	19	50

Q.8 How important do you think such training will be for your staff? Quel degré d'importance devrait être accordé à cette formation?	**English**	**Français**	**Total**
• Very important // Très important	32	16	48
• Important // Important	8	5	13
• Not important // Pas important	1	0	1
Q.9 The following represent training sessions. Please check all that would be of interest to your staff members. Les titres suivants suggèrent les sujets possibles. Veuillez vérifier ce qui serait d'intéret à votre personnel.	**English**	**Français**	**Total** 100%
• Alzheimer's Disease: What it is. // La maladie d'Alzheimer: qu'est-ce que c'est.	38	16	20%
• How to work with families // Comment travailler avec les familles.	41	21	23%
• Difficult behaviours // Le comportement difficile du patient.	41	21	23%
• Daily living // Les activités quotidiennes.	39	17	17%
• The stress of caregiving // La tension nerveuse chez les aides soignantes.	36	14	18%
Q.10 Please comment generally on how the training and education of caregivers could be improved. Est-ce qu'il y a des sujets qui devraient être étudiés mais qui n'ont pas été mentionnés ci-dessous?			
• Most common responses related to communications and stress (burn-out) among caregiving staff.			
• Next most common responses related to approaches to the resident, involving integration of staff with patient, understanding the patient's history and effectively dealing with families.			

Appendix B

Validation Questionnaire

General Impression

1. Does this curriculum fulfill the aim of providing basic training for caregivers of people with Alzheimer's Disease in long term care?

Please explain:

Evaluation

2. How well does the reflective writing or story telling by caregivers, as outlined in the reflections activity in each module, fulfill the evaluation component of the training?

Very Successfully Successfully Adequate Not adequate Inappropriate

Please describe other methods of evaluation that would better suit the needs of caregivers.

Additional Comments on the Overall Curriculum Package:

MODULE ONE

Please add any additional comments about Module One at the end.

Content

1. Is the content appropriate for the needs of the learners?
   Too basic   Appropriate   Too complex

2. What content is missing from this module?

3. Are the stated objectives in this module met?
   Very Well Indeed   Adequately   Just Barely   Not at all

Support Materials

1. Do the overheads add to the presentation of the content?
   Excellent   Very Good   Good   Not Very Good   Poor

2. Are the overheads clear and easy to read?
   Excellent   Very Good   Good   Not Very Good   Poor

3. Are the handouts valuable to the learner?
Excellent Very Good Good Not Very Good Poor

4. Are the handouts visually attractive, and easy to read?
Excellent Very Good Good Not Very Good Poor

Teaching Methods

1. Do the teaching methods address different learning styles? ☐ Yes ☐ No
If no, please explain:

2. Do the teaching methods successfully convey the content to the learners?
☐ Yes ☐ No
If no, please explain:

3. Are there other teaching methods that could have been employed in this module?

Worth

1. In your opinion, what experiences, knowledge, or activity, included in this module, would be most meaningful for a caregiver?

2. In your opinion, what experiences, knowledge or activity, included in this module, would be least meaningful for a caregiver?

Timing and Sequence

1. Is the progression of activities within the module logical? ☐ Yes ☐ No
   If no, please explain:

2. Has adequate time been allowed for each activity in the module? ☐ Yes ☐ No
   If no, please explain:

Please add additional comments on Module One:

The questions for Modules Two, Three and Four were identical to those asked for Module One.

Appendix C

Pride in Alzheimer's Care

Pride in Alzheimer's Care

Table of Contents

Pride in Alzheimer's Care

Introduction

Pride in Alzheimer's Care is a unique training curriculum that was developed with two guiding principles in mind. The first principle states that those who live with dementia deserve to receive care that sustains their rights, preserves their dignity and maintains their pride of themselves. The content of this curriculum teaches that care for those who live with dementia must be individualized, adaptive and person-centered. The term "person-centred" means that care fits the needs of the person, rather than the person being expected to fit the expectations of the care. Indeed, every effort is made to enable participants in the training to learn through the eyes and hearts of the people living with Alzheimer's Disease.

The second critical principle of this training is that caregivers as learners deserve to receive training that suits their unique needs, strengths and challenges; that is, each training session should be "learner-centered." This curriculum was developed to deliver training that is theoretically sound, practical, learner-centered and fun. It is intended to draw on the experiences and insights of staff already "on the job." This training helps caregivers learn essential skills and knowledge, so that they can be proud of the care they give. To ignore the needs of staff who provide direct service would compromise the quality of the care delivered and thus the quality of life enjoyed by those living with Alzheimer's Disease.

This curriculum, then, delivers training that not only preserves the "**pride**" of those who live with Alzheimer's Disease but also pays careful attention to the "**pride**" with which knowledgeable direct care providers deliver their care.

Audience

This curriculum was written primarily for caregivers who work in long term care facilities, but who may have little experience working with residents with dementia. However, the curriculum is written in such a way that all those who have direct contact with people who have Alzheimer's Disease and related dementia will benefit from the training.

Facilitator

The facilitator is an integral part of the curriculum. The facilitator should have some experience in delivering training, should be enthusiastic, should come to each session well prepared, and should have an adequate knowledge of the material. Additionally, facilitators should have expertise in drawing out life experiences from participants and helping them become aware of the wisdom of their personal and practical knowledge.

Physical Setting

If possible, training should be held in a room that is sound proofed to overhead paging systems and individual resident alarms. Personal pagers, beepers, and telephones should be either turned off or turned to silent alarm to minimize interruptions. The room should be equipped with tables arranged in a U-shape to facilitate face-to-face contact and discussion.

Psychological Setting

Learning is a risky business, and participants need a psychologically "safe" place in which to learn. Participants need to be reassured that there is no such thing as a stupid question or answer, and need to be told that every participant is expected to extend this same consideration to every other person in the group.

Confidentiality is also an important aspect of this training. Since the participants will be discussing situations and residents from their own place of work and their own performance, they need to be assured that their conversations will not be discussed or repeated outside the context of the training sessions.

Lastly, learning should be fun. Participants are making a time commitment to the training sessions - at least eight of their precious non-working hours. The subject matter and often the working conditions are very serious because they are, after all, caring for those with a progressive, non-reversible disease. Therefore, learning about how to find joy and happiness in caring for those who live with Alzheimer's Disease is, and ought to be, a priority.

Preparation

Pride in Alzheimer's Care is a very interactive training program. The materials have been prepared with careful attention to the learning needs and specific requests of caregivers themselves. The facilitator must become completely familiar with the program before implementation.

Each module contains activities that are meant to be used consecutively, because each activity complements the previous one. Time frames are suggested for every activity. The time assigned to the coffee break and the reflective activity in each module are flexible and should be used to make adjustments to the approximate time of 180 minutes planned for each session.

The curriculum has been written to accommodate eight to ten participants per session. To maximize peer learning, participants should attend from different facilities.

Manual Features

The Manual is divided into four modules. These modules are:

I. Communicating in Alzheimer's Care
II. What is Alzheimer's Disease
III. Stress in the Workplace
IV. Working with Families

Each module contains a specific list of materials and equipment needed to complete the training. In addition to this list, the facilitator will need one copy of each overhead transparency and sufficient copies of each handout. If the facility in which the training is being conducted does not have an overhead projector, the overhead transparencies can be used to create handouts for the participants.

Each activity includes special notes to the facilitator to clarify the intent of the activity as well as a comprehensive method that outlines, step by step, exactly how to facilitate the learning process.

Since individual learners are different in their preferred approaches to learning (sometimes called a learning style), the program has incorporated a variety of activities. In general, four types of activities are provided. Those which begin:

- with a discussion of ideas presented through reading, talks or lectures;
- by using ideas to develop alternative methods for doing something;
- with an actual experience or testing out of an alternative strategy; and
- with thinking about, reflecting on and discussing an experience

Evaluation

Each module includes a personal reflective activity that is integral to the learning process. Writing or telling a story of their own experiences at work incorporates learning at several levels. In this activity, participants should be encouraged to think about what they have learned, to try the new learning out in actual practice, to figure out whether such trials worked or not, and in the safety of the training group, to tell others what happened. More learning is fostered in the group by discussion, learning from others' experiences, and getting feedback on how to do it better. This kind of reflective activity also evaluates whether the knowledge and skills that each module purports to teach have been understood, and are being used in the work setting.

A general program evaluation is included at the end of the last module. The evaluation is a subjective questionnaire that captures reactions rather than specific content responses. More expressive narrative responses are captured in the program summary and wrap-up.

MODULE I:
COMMUNICATING IN ALZHEIMER'S CARE

Time Required

- 180 minutes
- 20 minute break included

Facilitator Preparation - General

- ✓ Flip chart, paper, masking tape and regular and dry erase (water soluble) markers
- ✓ Appropriate number of copies of Module I Handouts 1.1-1.4
- ✓ Tape player and quiet music cassette
- ✓ Overhead Projector and Module I Overheads 1.1-1.5
- ✓ Extra writing materials (pens and paper)
- ✓ Optional: One 'squoosh' ball (soft 2 inch pliable balls) for each table of participants to relieve stress throughout session
- ✓ Optional: Bag of Hard Candies used as condiments (to be evenly distributed amongst learners' tables)
- ✓ Package of 3x5 inch cards

Introductions **25 minutes**

Preparation:

- Overhead projector and screen set up ahead of time
- **Overhead 1.1: Cartoon: For Better of for Worse**

Method:

- ✓ Introduce yourself. Welcome the learners and express enthusiasm for the program that the learners are about to begin.
- ✓ Put up **Overhead 1.1: Cartoon: For Better or for Worse**
- ✓ Share the joke with the group.
- ✓ Ask the participants to number around the group 1,1,2,2,3,3,4,4, etc. Those with the same number form a pair.
- ✓ Ask the participants in each pair to introduce themselves to each other and to share a specific difficulty that they have had communicating with a resident in their facility. Tell them when they have finished introducing themselves to each other, they will be called on to introduce their partner and their partner's difficulty to the rest of the group.
- ✓ Give the participants 10 minutes to talk.
- ✓ Go around the large group and give each person 1 minute to introduce their partner.
- ✓ Thank them for their introductions and tell the group that they will be learning some ways to help them communicate better with their residents.

Agenda **2 minutes**

Preparation:

- Flip chart paper, masking tape, and markers.
- Prepare a flip chart page ahead of time showing the **Agenda (Flip chart 1.1: Agenda)**.
- Post the Agenda in a prominent place in the room using masking tape and leave it up for the duration of the session.

Method:

- Go over the agenda, mentioning that most of the time will be spent on:
  - identifying the problems in communication,
  - learning how to fix these, and
  - practising new skills.
- Add that the group may not complete all items on the agenda.
- Tell the learners that the group will take time to discuss the important issues

Flip chart 1.1: Agenda

Introductions	25 minutes
Agenda	2 minutes
Discussion Topics	3 minutes
Communication Problems – Helps and Hindrances	30 minutes
Visualisation Activity	30 minutes
- BREAK -	20 minutes
Mini-Lecture	5 minutes
Communicating: "Getting It Right"	25 minutes
Communicating: "Doing It Right"	30 minutes
Reflections	10 minutes

Discussion Topics **3 minutes**

Preparation:

- Overhead projector and screen set up ahead of time
- **Overhead 1.2: Discussion Topics** or prepare a flip chart ahead of time showing the discussion topics of the module.

Method:

- Put up **Overhead 1.2: Discussion Topics**
- State that during this session we will talk about:

  ✓ What gets in the way of listening and understanding
  ✓ How to talk to persons with Alzheimer's Disease
  ✓ How to listen to persons with Alzheimer's Disease

Overhead 1.2

Discussion Topics of Module I

- ✓ What gets in the way of listening understanding
- ✓ How to talk to persons with Alzheimer's Disease
- ✓ How to listen to persons with Alzheimer's Disease

Communication Problems **30 minutes**

Preparation:

- **Overhead projector and screen set up ahead of time**
- **Overhead 1.3: Common Problems in Communication**
- Dry erase or water soluble pens for overhead

Facilitator Notes:

As a result of this activity, learners will understand that others share similar problems and that there is more to listening than paying attention. Communication is a shared practise that tends to be taken for granted between cognitively intact individuals. Caregivers need to be especially aware of the complexity of the communication process, and its interactive components, so that they can effectively compensate for those who have Alzheimer's Disease.

Method:

- Put the group into the same pairs as in the Introduction activity.
- Ask the participants to think back, now, to the Introduction activity they just did and discuss, in pairs, the problems they had with communicating with their resident.
- Ask them to make two columns on a sheet of paper. At the top of one column put the title "What does my resident do (or not do) that contributes to the problem?" On the other column put the title "What do I do (or not do) that contributes to the problem?"

- Tell them that as they are discussing their communication difficulties with their partner, they should make notes in the appropriate columns.
- Give them 10 minutes to discuss their problems and make notes.
- Put up the **Overhead 1.3: Common Problems in Communication** and briefly explain.
- Go around the room and ask each pair for one of the items they have entered on either of the two columns they have developed.
- Look for a similar problem on the overhead.
- Appoint a volunteer to put a star beside the most similar problem on the overhead with a dry erase marker so it can be erased later
- Keep going around the group until all problems are recorded.
- Look for problems that have been identified with many stars, others that have none and discuss them with the group.

Overhead 1.3

Common Problems in Communicating

Ignoring

Faking Attention

No Eye Contact

Distracting behaviour

Getting Ready

Selective Listening

Negativity

Noisy Environment

Non-verbal language

Feelings about the other person

Fatigue

Voice

Talking down or over

Visualisation Activity: The World of a Resident with Alzheimer's Disease

30 minutes

Preparation:

- The material on the next two pages is a script that you are going to read to the participants of your group.
- Practice reading the script out loud to yourself several times ahead of time. Try out different pacing/speech, vocal expressions, etc.
- It should be read slowly, pausing between sentences. However do not pause too long or participants will go to sleep.
- Prepare **Flip chart 1.2: Discussion Questions** ahead of time listing the discussion questions that appear following the script and have this page ready to display once you have finished reading the script.

Facilitator Notes:

This activity requires a high degree of involvement from the facilitator and the learners. You should take time to emphasise the importance of losing oneself in the memory. How much the learner gets out of the exercise is proportional to how vividly they are able to visualise. The success of this exercise is also based on the expression that you can convey in reading the passage. This certainly may be potentially threatening for some participants. Careful attention should be given to debriefing the participants after the activity. Ensure that emotions and issues are acknowledged before moving on to the next module.

Method:

- Tell the participants to relax and assume the most comfortable position they can. Tell the learners that they are to imagine themselves as the person with Alzheimer's Disease and to really let themselves 'get into' the situation that they hear being described.
- Tell them that after this activity, they will be asked to write down some of their reactions and feelings to the situation.
- Invite them to close their eyes and listen carefully.
- Read the script slowly and pause between sentences to give your listeners time to visualize your words.
- The script should take approximately 5 minutes to read.
- Post the flip chart list of discussion questions when the visualization is over.
- Ask the participants to consider the answers to the questions first quietly by themselves, then to share these answers with their partner.
- Finally, ask participants to share some of their responses with the large group.

"...You are sitting near a window in a recliner. It is so sunny that you have had to squint for a long time. You finally close your eyes..... You can feel the heat of the sun on your face. You can hear father's voice, "get along Doll, git up Jip.." urging the horses to get the load in and the lazy clumphf, clumphf, clumphf of the horses moving slowly toward the barn. You can see Momma's back swing

down, swish up, and over her shoulder with the fork filled with hay, again, and again, and again, just like the last two thousand times that it has today. The back of your neck is wet with sweat but you are too tired from the hayin' to bother to wipe it away.

Suddenly, someone you don't know is standing in front of you, speaking at you. You just can't make out who is there. The glare from the sun is blinding you. You don't recognise anyone. You are frozen in fear because Momma warned you about hobos who would just as soon as kill you as look at you. Momma had said to run away from them but you can't move. Something else is said but you just caught the end of a few words. You didn't understand, you didn't hear the first part. Words again, louder and louder. Someone is trying to grab your arm.

VOO NEE GO VADROOM?!

You have no idea what is being said. Louder and faster, you hear.

VOO NEE GO VADROOM!!!!

You sense that someone is angry and in a hurry. You do not know what to say. You can't think of any words. You are scared and alone, so alone...Just as quickly, silence again. You can feel your fear like a rope around your neck....

(Long pause)

How are you feeling right now?

(Long pause)

What made you feel that way?

(Long pause)

Let yourself drift back to the sunshine. When you are ready open your eyes slowly and come back to the here and now."

When everyone has opened their eyes, ask them to think quietly for a few minutes about how they feel. Then ask them to turn their attention to the questions on the flip chart and spend a few minutes, at first quietly by themselves, thinking about their responses and then share these answers with their partners. Finally, discuss the questions as a group allowing sufficient time for those who need to work through strong reactions to the activity. Keep in mind that there may be some individuals for who this activity causes more intense reactions.

Flip chart 1.2: Discussion Questions

- How did you feel during the activity?
- What did the speaker say or do that made you feel that way?
- What could the speaker have done differently?
- If you were the resident, what would you have done?

While you are getting your tea, coffee, juice, think and talk about the ways that you have seen residents react the same way that you did in this activity.

- BREAK- **20 minutes**

Mini-Lecture: 5 minutes

Aging and Alzheimer's Disease

Preparation:

- Overhead Projector and screen set up
- Dry erase or water soluble Pens
- **Overhead 1.4: Aging and Alzheimer's Disease: Effects on Communication**
- Photocopies of **Handout 1.1: Aging and Alzheimer's Disease: Effects on Communication**

Facilitator Notes:

This mini-lecture will consolidate facts about aging and Alzheimer's Disease. Learners should have some awareness of the resident's world and understand some of the difficulties they face. Learners should also have an awareness of the importance of good communicating skills.

Keep the mini-lecture to a maximum of 10 minutes – shorter would be even better.

Method:

- Give out **Handout 1.1: Aging and Alzheimer's Disease: Effects on Communication**
- Use the facilitator notes **"How Aging and Alzheimer's Disease Affects Communication"** to develop your talk for the learners. Do not read the notes – use them.
- Present the facts simply. Do not use complicated words or sentence structure.

- Tell the learners to use the handout to write down just the important points as you talk.
- Put up **Overhead 1.4: Aging and Alzheimer's Disease: Effects on Communication**
- To review, ask participants to help you fill in your overhead after you have talked. Ask the learners, "What are three factors that can affect communication in people who are aging normally?" Using the dry erase or water soluble pen, fill in the overhead with responses given by the participants. Then ask the learners, "What are some factors that affect communication in people with Alzheimer's Disease?" Fill in the overhead with responses given by the participants.

Overhead 1.4

Aging and Alzheimer's Disease: Effects on Communication

Normal Aging:

1. ______________________________
2. ______________________________
3. ______________________________

Alzheimer's Disease:

1. ______________________________
2. ______________________________
3. ______________________________

Overhead 1.4

Aging and Alzheimer's Disease: Effects on Communication

4. ______________________________

5. ______________________________

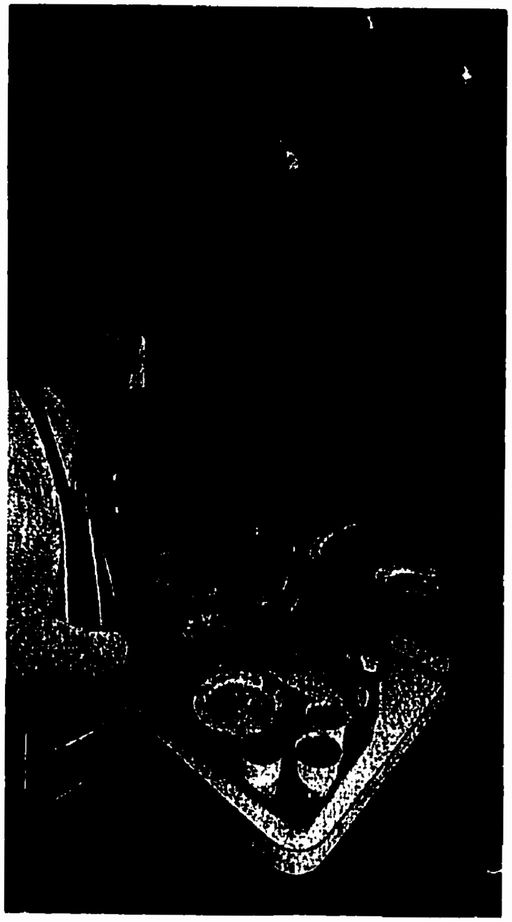
6. ______________________________

7. ______________________________

8. ______________________________

9. ______________________________

____



Handout 1.1: Aging and Alzheimer's Disease: Effects on Communication

Aging (factors that <u>may</u> occur in natural aging)

1. ____________________________________

2. ____________________________________

3. ____________________________________

Alzheimer's Disease (factors that <u>may</u> occur in resident's with Alzheimer's Disease -- some days more, some days less)

1.________________________

2.________________________

3.________________________

4.________________________

5.________________________

6.________________________

7.________________________

8.________________________

9.________________________

Facilitator Mini-Lecture Notes: How Aging and Alzheimer's Disease Affect Communication

Aging is a healthy state of being. In normal aging, the slight declines in vision, hearing and response time are not severe enough to impair communication to any noticeable degree. However, when normal aging effects are combined with disease, accident, lack of fitness and poor nutritional choices, communication may deteriorate more noticeably.

NORMAL AGING: (Factors that may occur)

1. Vision Loss - may begin in the late 30s leading first to a need for reading glasses. Many older persons have difficulty focusing on objects close at hand, and less problem focusing on objects farther away. The age-related changes may combine with existing vision conditions (i.e., near-sighted, far-sighted, astigmatism). Adapting to changes between light and dark takes longer with increasing age. As people age, there may be increases in diseases of the eye, such as cataracts and glaucoma.

Older persons with poor vision may have difficulty communicating if they cannot clearly see those with whom they are talking, cannot see printed material, have difficulty writing, and cannot easily discern facial or body expressions.

2. Hearing Loss – begins in the twenties and declines very gradually so that by age 65, some individuals **may** have up to 70 per cent hearing loss. In fact, most older adults have some degree of hearing loss. Such losses may affect their conversational ability. Men often have greater hearing losses than women, likely due to environmental conditions.

Generally the loss is typified by a decrease in the ability to hear sounds at higher pitches (e.g., hissing sounds such as sh, th, f, ch); consonants are harder to hear than vowels; and it is harder to filter out back-ground noise. As well, it becomes more difficult to locate the source of sounds.

3. Slow down of physical response time – The time needed to process stimuli, (visual, smell, taste, hearing, pain, touch, temperature, muscular tensions, and balance) becomes longer with increasing age. This is especially true in novel or emergency situations. Response time is affected, not only in the time it takes to receive and process the information, but also in the time it takes to physically react to stimulation. Although there may be a slowing in processing, the accuracy and effectiveness of the response may not be impaired at all. Nevertheless, there is significant stress involved (e.g., anxiety about being slow) which may further decrease response time.

ALZHEIMER'S DISEASE: (Communication difficulties that may occur in AD, either alone, in combination, and in varying degrees of severity and frequency)

1. Confusion - The person with Alzheimer's Disease has difficulty in expressing him or herself, words become jumbled and lack grammatical structure or sense. Standard greetings and often used expressions may be perfectly intact giving others the impression that the person is cognitively well when they actually are not. At other times, a correctly worded greeting will be expressed at the wrong or inappropriate time.

2. Difficulty in maintaining concentration - A person loses the ability to concentrate for longer than a few minutes at a time. It is very difficult and frustrating for a person with Alzheimer's Disease to remember what they have just said, find the words to say what they want to say, attend to and understand what is being said to them. Often this results in jumbled language that makes no sense. Sometimes, people with Alzheimer's Disease withdraw from trying to communicate because it is too difficult to 'keep it altogether'.

3. Loss of Memory- Person may ask questions repeatedly. They either cannot remember what was said, or did not understand, or have no memory on which to base a response or have no memory of having already asked a question. They cannot remember what they said themselves, nor can they remember what happened or was said to them.

4. Cannot find the right words - Things or people are often incorrectly labelled. People are called "she" and "he", because names are forgotten. Conversation is difficult for the person with Alzheimer's Disease because, despite the thought being present and the desire to speak, the appropriate words are absent. This condition of language impairment or aphasia has several subtypes. Receptive aphasia refers to difficulties understanding written or spoken language, and expressive aphasia refers to difficulties with expressing spoken or written language.

5. Unable to put words with objects – This condition which is called anomia refers to difficulties with naming or labelling people or objects. Things are either mislabelled or called *thingamajigs* or *whatchmacallits*. Words that are used least often are the most quickly lost. Instead of labels, the thing is described by its function; for example, a fork is a "thing that picks up food."

6. Rhyming Words - Sometimes words are replaced by other words that have the same ending sounds but different beginning sounds. For example, "Get me my boat," might be used instead of "Get me my coat."

7. Failure to understand spoken or written words - Often people with Alzheimer's Disease can read written words very well but they have no comprehension of the meaning of the words or they cannot make sense of the words that form a sentence. They may be able to identify the words 'book, on, and table' however, they may not understand or be able to make sense of 'The book is on the table".

8. Figures of Speech - words that have no literal meaning can be very confusing for those who have forgotten idiomatic expressions or can no longer comprehend them. For example, 'It is raining cats and dogs.' is an idiomatic expression that is understood to mean "It is raining heavily." However, to the person with Alzheimer's Disease, the expression, taken literally, is cause for great confusion and misinterpretation.

9. Conversation - There are unwritten rules in conversation such as turn taking, voice inflections, personal space, eye contact and waiting for responses. These may all be forgotten by a person with Alzheimer's Disease. Thus normal conversation ceases to exist. What is said to a person with Alzheimer's Disease may not be understood by them and they, in turn, may not be able to express themselves in a way that makes any sense to us.

Communicating: "Getting It Right" **25 Minutes**

Preparation:

- Flip chart paper, markers, masking tape
- Photocopies of **Handout 1.2: Tips for Communicating With a Person who has Alzheimer's Disease (3 pages)**

Facilitator Notes:

This is a brainstorming activity. Now that the learners understand what can go wrong in communication with persons with AD, this is an opportunity for the learners to come up with alternatives for "getting it right". **Handout 1.2: Tips for Communicating with a Person who has Alzheimer's Disease** addresses individual needs and abilities. The handout is meant to be used as a resource for caregivers. The first page deals with caregiver's speech delivery, while the second deals with non-verbal communication tips. The third suggests aids for interactive communication between someone with Alzheimer's Disease and the caregiver.

Method:

- Divide the group in half and give each small group flip chart paper. If the two groups cannot be separated so that noise from one group does not interfere with the other, then it is better to do this as one group.
- Ask them to think about times when they felt that they were communicating well with their AD residents.
- Ask them to write down everything that they thought they were doing well.

- Give them 5 minutes to write down as many points as they can.
- Tell the participants that quantity is more important than quality.
- At the end of 5 minutes, ask each group to tape their sheets to the wall.
- Give out **Handout 1.2: Tips for Communicating with a Person who has Alzheimer's Disease: A. What I can do to Improve my Speech, B. What I can do to Improve my Non-verbal Communication, and C. Helping a Resident with Alzheimer's Disease to Communicate (3 pages)**
- Tell the learners that the handout lists ways to communicate well with people with Alzheimer's Disease.
- Ask for a volunteer to read the points one at a time.
- Ask another volunteer (one from each group if you have two groups) to put a check beside the items on the group lists that are the same as or similar to the points on the handout as these points are being read out loud. Pause at the end of each statement to make sure all relevant points have been checked.
- If participants suggest a point that is not on **Handout 1.2**, take time to acknowledge the suggestion and ask the participant to explain.
- If the participants' lists do not have a same or similar item to the points read out, provide an example if appropriate.
- Conclude the activity by praising and acknowledging how much the group already knows about good communicating.

Handout 1.2: Tips for Communicating with A Person Who Has Alzheimer's Disease

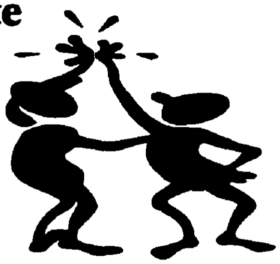
A. What I Can Do To Improve My Speech:

- Think before you speak.
- Speak slowly and clearly.
- Speak to the person as an adult.
- Use the person's name - formally at first. Some may have a nickname which may eventually be more appropriate.
- Learn what the person likes to be called.
- Use a friendly tone of voice.
- Start your message with a personal compliment such as noticing a pretty sweater.
- Speak in simple, short sentences.
- Always introduce yourself. They may not remember you.
- Repeat what you have said if it was not understood. Use the same words as before.
- Use words that the person will recognize.
- Use positive language: "You can do this," rather than "Don't do that!" or "You can't do that."
- Always include the person in the conversation. Do not talk about them as if they were not there.
- Offer only two choices at a time.
- Speak in a straightforward manner, avoid figures of speech.
- Use an up-beat sense of humour when appropriate.
- Break tasks down by doing them one step at a time
- Ask questions that have Yes or No answers.

B. What I can do to Improve my Non-verbal Communication

- Approach the person slowly from the front and slightly to the side. Do not block straight ahead exit – it is threatening.
- Make eye contact; try to ensure that your head is at their eye level or below.
- Start conversations with a friendly touch on the hand or arm.
- Give extra time to respond.
- Smile, be patient.
- Use gestures to help the message be understood.
- Keep a comfortable distance between you and your resident.
- When about to touch the person, go slowly and be deliberate. A lighter touch may go unnoticed or be misinterpreted. Be ready to withdraw, if the person's body language becomes tense.
- Touch often, if the touch is welcomed. Touch in such a way as to let the person know that you care.
- Use actions rather than words to demonstrate or mime what needs to be done. Go through the motions.

C. Helping a Resident with AD to Communicate



- Try to fill in the missing word.
- Reassure the person and do not argue.
- Emphasise what the person knows and can comment on rather than what they do not know.
- Start a conversation, rather than wait for them to start - they might not know how to start.
- Turn off the television or radio. If this is not possible then turn the person away from the source of the noise and then begin speaking.
- Watch the person's body language to understand what message is trying to be sent.
- Look for a meaning behind the spoken words, especially if the words do not make sense or the person is becoming upset with the words that he or she is using.
- Appreciate their sense of humour.
- Stay involved with the conversation by talking back, smiling, nodding and maintaining eye contact.
- Give immediate positive feedback.
- If a person forgets or loses their train of thought, repeat the last few words of what they were saying or summarise what they said.
- Give the person plenty of time to reply.
- Understand that what the person can do today, they may not be able to do or understand tomorrow. What they cannot do today, they may well be able to do tomorrow. They are not playing games or trying to manipulate, so do not lose patience with them.

Communicating: "Doing It Right" **30 minutes**

Preparation:

- Flip chart and markers
- Have 3x5 inch cards prepared with an activity and a letter (as below) on each one. Make sure that you have enough cards so that each pair receives a different activity.

a. Brushing teeth
b. Putting on socks
c. Eating vegetables
d. Sweeping a floor
e. Face Washing
f. Getting into a Bath

Example: e. Face washing

- Photocopies of **Handout 1.3: Communicating Demonstration: "Saying It Right"**

  *If you have 10 participants, there will be 5 presentations, and each pair will need 1 handout for assessing each of the presentations done by other pairs. (5x4=20 handouts)

Facilitator Notes:

This is an opportunity for the learners to act on what they know. Emphasise that their presentation can be no longer than 2 minutes. Tell them that, since they have only a very limited time to present, they may choose a very small part of their task to demonstrate their skills.

Be aware that acting in front of a group is very difficult for many learners. Emphasise the importance of practising a new skill.

- Be very encouraging and supportive of all groups. Be available for questions and problem solving. Be enthusiastic and vocal about how good they will all be, whatever their acting talents.

  OPTION: Depending on individual needs, group size may need to increase. If participants are anxious about role playing, increase the number of participants in the group to four. Respect the choice of those who do not wish to participate.

Method:

- Ask the learners to work with a partner.
- Have each pair choose a card.
- Tell them that you will give them 5 minutes to prepare a demonstration showing how they would communicate with a resident to help them with the activity described on their card.
- Tell the learners that one of them is to act the role of the resident and the other, the caregiver.
- Pairs will present in the alphabetical order of their cards.
- Have the participants prepare their presentations.
- Before the first presentation, inform the learners that while one pair is presenting, the other pairs will be making a list of five good communication skills that they see being demonstrated by the pair playing the roles. As each pair does their demonstration, the other participants are to keep track of the good communication skills that they see being demonstrated in the presentation.
- Pass out **Handout 1.3: Communicating Demonstration: "Saying It Right"**. You will need enough copies so that each partnership can assess each presentation (see Preparation)
- Tell the learners that they will have an opportunity to see what others have written about their presentation later.

- Provide copious amounts of positive reinforcement and encourage the use of **Handout 1.2: Tips for Communicating with Someone with Alzheimer's Disease** (handed out earlier).
- After each presentation, tell them what a great job they did.
- Give the observers one minute after each presentation to talk to each other about what they have seen. They should write down examples of good communication skills on their handouts, if they have not already done so.
- Collect the sheets after each presentation.
- When all presentations have been completed, give out the completed feedback sheets to the relevant presenters.
- Allow one minute for the pairs to review their sheets together.
- Put up **Overhead 1.5: Demonstrated Communication Skills**
- Ask each pair for one of their good communication skills from their feedback sheets and write it down on the overhead. Continue around the room with each partnership contributing one skill which has not already been listed until all good skills are written on the overhead.
- Go back to their posted brainstorming efforts on the wall and ask them to compare their brainstormed list of communication skills and their own presentation skills listed on the overhead. Mention that they have demonstrated many of the great skills that they had identified.
- Congratulate them on a job well done!

Handout 1.3: Communication Demonstration: "Saying It Right"

Names of Presenters: ________________________________

List good skills that the caregiver is demonstrating in communicating with a person who has Alzheimer's Disease.

____

____

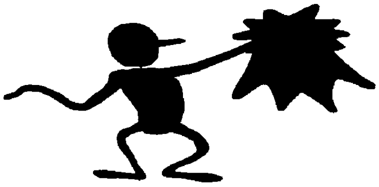
____

____

____

Mention one thing that they could have done better.

____



Overhead 1.5

Demonstrated Communication Skills

Reflections **10 minutes**

Preparation:

- Photocopies of **Handout 1.4: Reflections**
- Cassette tape of quiet music
- Cassette Player

Facilitator Notes:

This is an opportunity for the learners to put together what they have learned about communication and themselves. Encourage the learners to write as much as they wish.

Method:

- Tell the learners that they have an opportunity now to write about what they have learned and what it means to them.
- Tell them that this is their homework for the next session.
- Ask them to please bring their "**Reflections**" to the next session.
- Give them ten minutes or the time remaining.

- **Sincerely and earnestly, thank them for coming.**

Handout 1.4: Reflections

What did I learn about my own ways of communicating?

How does Alzheimer's Disease affect the way my residents talk to me?

What are five things that I can do to make myself a better communicator with residents with Alzheimer's Disease?

1. ____
2. ____
3. ____
4. ____
5. ____

What did I not understand today?

Choose one incident that happened this week that shows that I am a good communicator. Describe this incident on the back of this page and bring it with you for next session.

MODULE II:

WHAT IS ALZHEIMER'S DISEASE?

Time Required

- 180 minutes
- 20 minute break included

Facilitator Preparation - General

- ✓ Flip chart, paper, masking tape, markers – regular and dry erase (or water soluble)
- ✓ Appropriate number of copies of Module II Handouts 2.1-2.7
- ✓ Tape player and quiet music cassette
- ✓ Overhead Projector and Module II Overheads 2.1-2.4
- ✓ Extra writing materials (pens and paper)
- ✓ Optional: One 'squish' ball (soft 2 inch pliable balls) for each table of participants to relieve stress throughout session
- ✓ Optional: Bag of Hard Candies used as condiments (to be evenly distributed amongst learners' tables)
- ✓ Package of fine-tipped water soluble markers
- ✓ Cotton balls, 2 pair of oven mitts, two pair of glasses, Vaseline, a toothbrush and a pair of shoes

Welcome Back! 2 minutes

Preparation:

- None

Method:

- Welcome back the participants and express pleasure that they have returned for this session.
- Tell them that they will have a chance to practice their communication skills from last session and learn more about Alzheimer's Disease during this session.
- Tell them that, if they want to, they will have the chance to share their reflections from the last session with the group.

Icebreaker- Who Am I?

10 minutes

Preparation:

- Masking tape
- Have 3x5 inch cards prepared with names of famous people written on them. Have enough cards so that there is one for every participant.

Examples:

Princess Diana	Queen Elizabeth
Mickey Mouse	Popeye
Jean Chretien	Monica Lewinsky
Madonna	Bill Clinton
Céline Dion	Shania Twain

Facilitator Notes:

This icebreaker is used to practice the communication skills learned from the last session and provides an opportunity to reacquaint participants with each other.

Method:

- Ask participants to find a partner who they did not work with at the last session. Assign one if they have difficulty.
- Using masking tape, secure a piece of paper with a name on it onto the back of each learner.
- Tell the participants that they are all famous people and that they are to try and guess who they are.
- They are to ask their partner any kinds of questions with no limit on the numbers of questions, but the person who answers can only say "YES" or "NO".
- After they have discovered who they are, they can join other pairs who have not discovered themselves, and help out.
- Allow five minutes for this procedure.

Agenda **2 minutes**

Preparation:

- Flip chart paper, masking tape, and markers.
- Prepare a flip chart page ahead of time showing the Agenda **(Flip Chart 2.1: Agenda).**
- Post the Agenda in a prominent place in the room using masking tape and leave it up for the duration of the session.

Method:

- Go over the agenda, mentioning that most of the time will be spent on:
  - ➢ learning how Alzheimer's Disease affects the brain
  - ➢ experiencing part of the diagnostic process
  - ➢ recognizing behaviours that are a result of Alzheimer's Disease and those behaviours that may be caused by other treatable factors.
- Add that the group may not complete all items on the agenda.
- Tell the learners that the group will take time to discuss the important issues.

Flip chart 2.1: Agenda

Welcome Back	2 minutes
Icebreaker- Who Am I?	10 minutes
Agenda	2 minutes
Discussion Topics	3 minutes
Reflections Review	15 minutes
How the Brain is affected by Alzheimer's Disease	30 minutes
- BREAK-	20 minutes
Experiencing Alzheimer's Disease	30 minutes
Diagnostic Activity	25 minutes
The Causes of Alzheimer's Disease: A Crossword Puzzle	10 minutes
Observing the Behaviours Associated with Alzheimer's Disease	25 minutes
Reflections	8 minutes

Discussion Topics **3 minutes**

Preparation:

- Set up overhead projector and screen ahead of time
- **Overhead 2.1: Discussion Topics for Module II** or prepare a flip chart ahead of time showing the discussion topics of the module.

Method:

- Put up **Overhead 2.1: Discussion Topics for Module II**
- State that during this session we will talk about:
  - ✓ What happens in the brain with Alzheimer's Disease
  - ✓ What kinds of behaviours to expect from a resident who has Alzheimer's Disease
  - ✓ Trying to understand the world of a person with Alzheimer' s Disease.

Overhead 2.1: Discussion Topics of Module II:

Communicating in Alzheimer's Care

- ✓What happens in a brain with Alzheimer's Disease
- ✓What kinds of behaviours to expect from a resident who has Alzheimer's Disease
- ✓Trying to understand the world of a person with Alzheimer' s Disease.

Reflections Review 15 minutes

Preparation:

- Extra copies of **Handout 1.4: Reflections** from last session.

Facilitator Notes:

Emphasize that sharing notes or thoughts from their **Reflections**, although very beneficial for all, are personal choices.

Use the time judiciously. Try to incorporate the reflections of as many participants as possible. If the participants have trouble sharing, do not belabour the issue. Move on to the new material. On the other hand, if discussions have overrun the time allotted, try and draw conclusions before moving on to the new material.

Method:

- Ask participants to take out their **Reflections** from last week.
- State that you are going to ask them to share their thoughts from their reflections. Tell them that there are no wrong answers and that they are free to talk about their own experiences or to add to others' experiences.
- Tell them that they can share if they want to, but they do not have to.
- Ask them to talk about the incident they wrote about in their reflection.
- Give participants time to answer and be encouraging to everyone.

How the Brain is Affected by Alzheimer's Disease

30 minutes

Preparation:

- Overhead projector and screen set up
- Copy of **Overhead 2.2:**
  Parts of the Brain Affected by Alzheimer's Disease
- Photocopies of **Handout 2.1:**
  Parts of the Brain Affected by Alzheimer's Disease
- Extra fine-tipped water soluble markers
- Dry erase or water soluble pens

Facilitator Notes:

Make sure that you are well acquainted with the script for this activity. The bolded text indicates words or sentences that **must** be said.

Method:

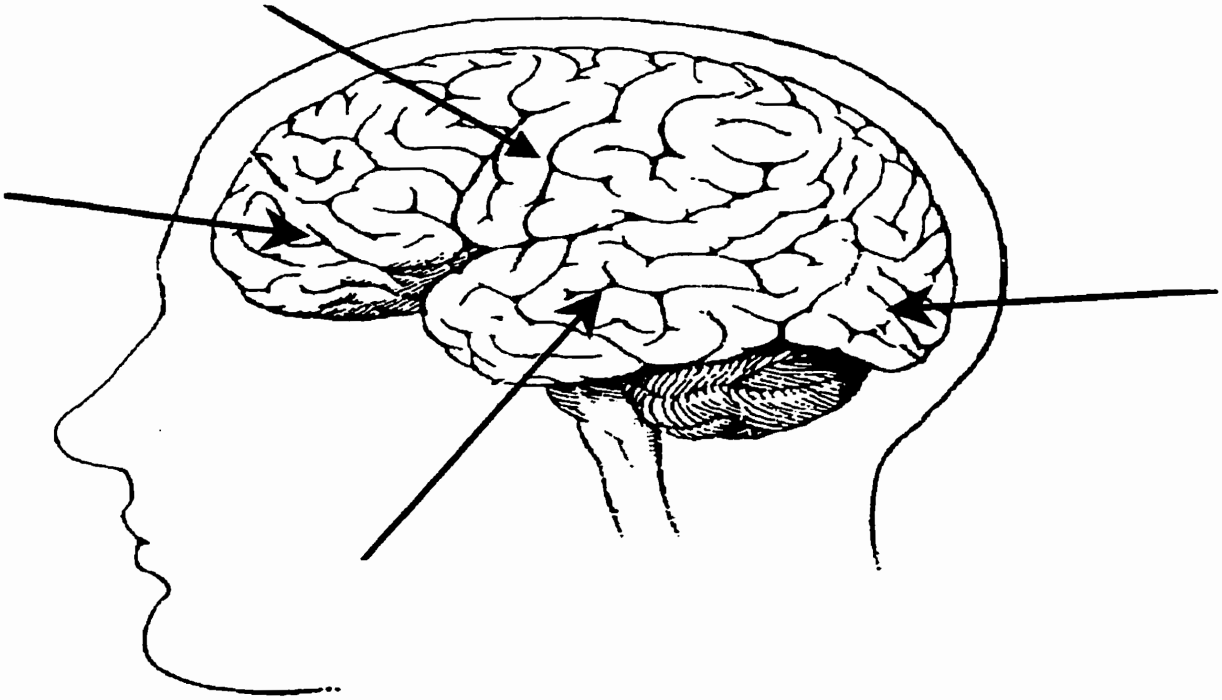
- Give each participant one extra fine-tipped water soluble marker.
- Ask the learners to make a fist with both hands, tucking the thumb under the fingers. Press the base of the hands together so that the fingers touch, and the forearms are pressed together from wrist to elbow.
- Demonstrate what you would like them to do.
- Tell the participants that what they have in front of them is a **model of their brain** as if they are looking at it from the front.

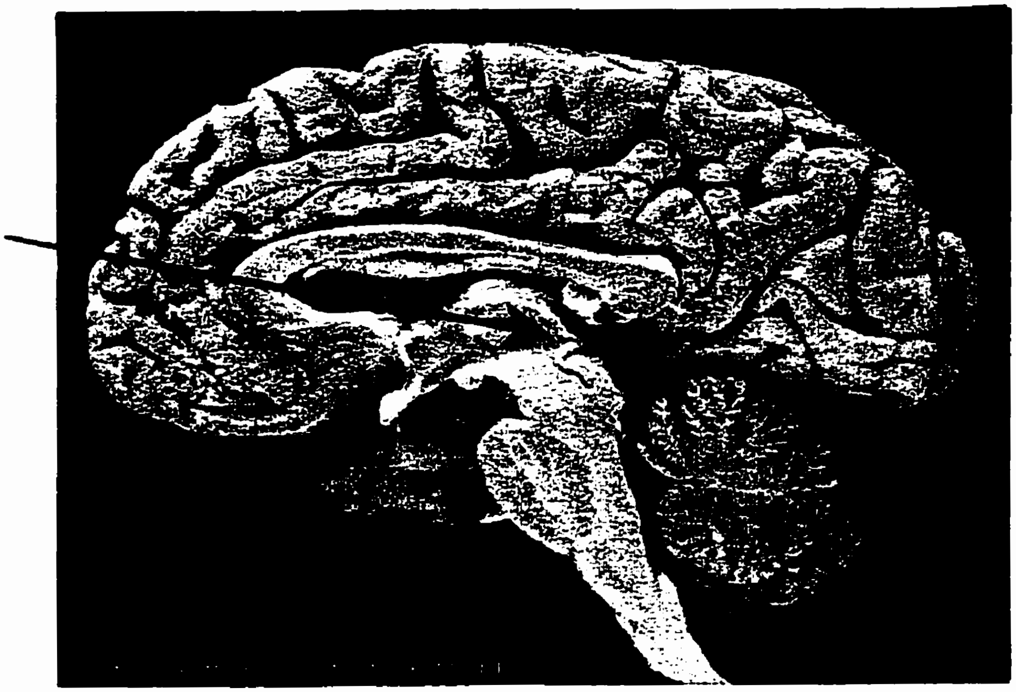
- Put up **Overhead 2.2: Parts of the Brain Affected by Alzheimer's Disease** and label the areas with a dry erase or water soluble marker as you talk about them. Refer to the overhead as you are talking about the brain based on the following bolded script. Use **Overhead Reference 2.2** to ensure you correctly label the overhead
- Your **forearms represent your spinal cord and your wrists represent your brain stem.** Just as you have two hands, you **have two halves to your brain, although they are very interconnected to each other. Each side is roughly the same size and shape. Each half is divided roughly into four sections.**
- Tell the group that they can use one hand to **write with their pens on their other hand to label the parts of the brain.** Ask them **to put a star beside the label on their hands to show areas of the brain that are most severely affected by Alzheimer's Disease.**
- Say to the group that **the frontal lobe (index finger and the top of the thumb) is directly in front of you. It is the part of the brain is in charge of organizing, planning and carrying out ideas. It is badly affected by Alzheimer's Disease.**
- Put a star on your index finger and write frontal lobe on it while I put the label on the overhead.
- The **middle of the back of your hand represents the temporal lobe**. It is the part of the brain that is in charge of **language and speech**. It is **badly affected by Alzheimer's Disease.**
- Label the temporal lobe on the overhead and have participants label the back of their hand.
- **The back of your fist and your little finger represents the occipital lobe.** It is the part of the brain associated with **sight.** It is **not badly affected** by Alzheimer's Disease. Tell the participants to label the occipital lobe on their hand while you label it on the overhead.

- **Behind the frontal lobe and above the temporal lobe, about where your second finger is located is the parietal lobe. It makes sense of space. This includes your thoughts about spatial orientation, and about your body's position in space and any activities that involve body orientation – like walking down stairs. It is moderately affected in Alzheimer's Disease.**
- Tell participants to label the parietal lobe on their hand while you label it on the overhead.
- The next part of the brain that we are interested in is the hippocampus. It is located about where your second fingers touch the palms of your hands. You can see that it is located at about the centre of the brain. The hippocampus controls **short and long term memories. It is very badly affected by Alzheimer's Disease.**
- Tell them to label the hippocampus on their hand, while you label it on the overhead. Tell them to put a star beside it.
- Turn off the overhead projector.
- Give out **Handout 2.1: Parts of the Brain Affected by Alzheimer's Disease.**
- From the labels that they have written on their hands, have them label the diagram of the brain in front of them.
- Tell them that they may work with a partner if they would like to.
- When they have finished, turn the overhead back on and have them check their labels.

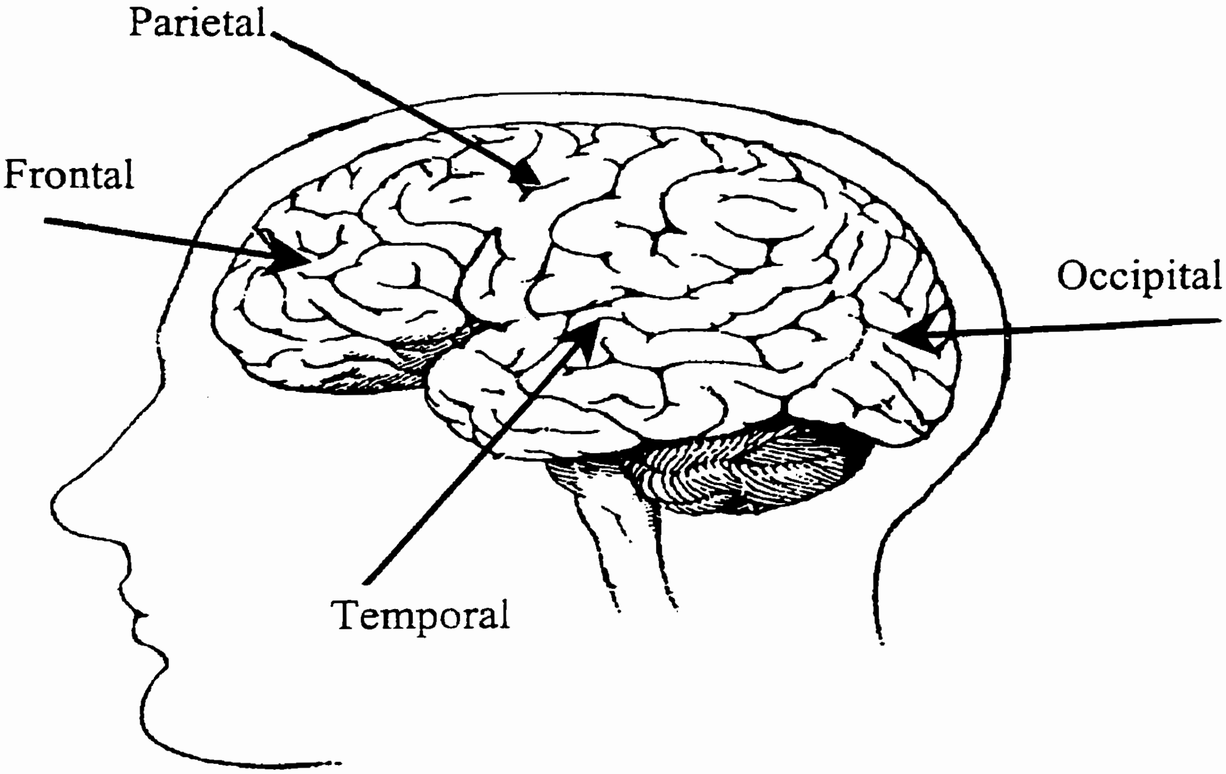
Overhead 2.2

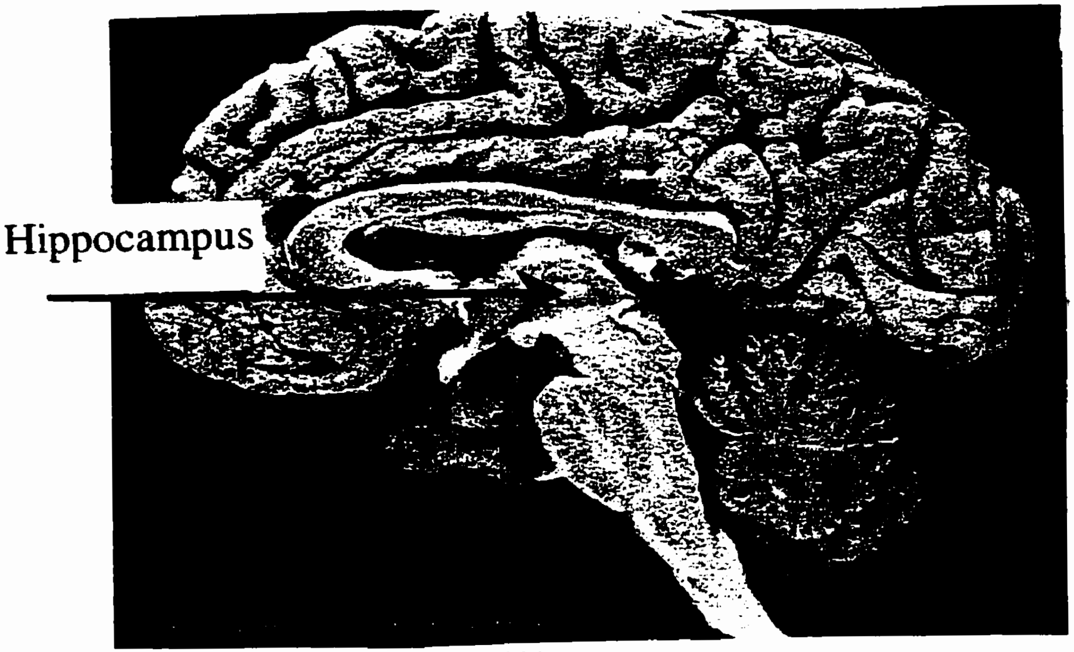
Parts of the Brain Affected by Alzheimer's Disease



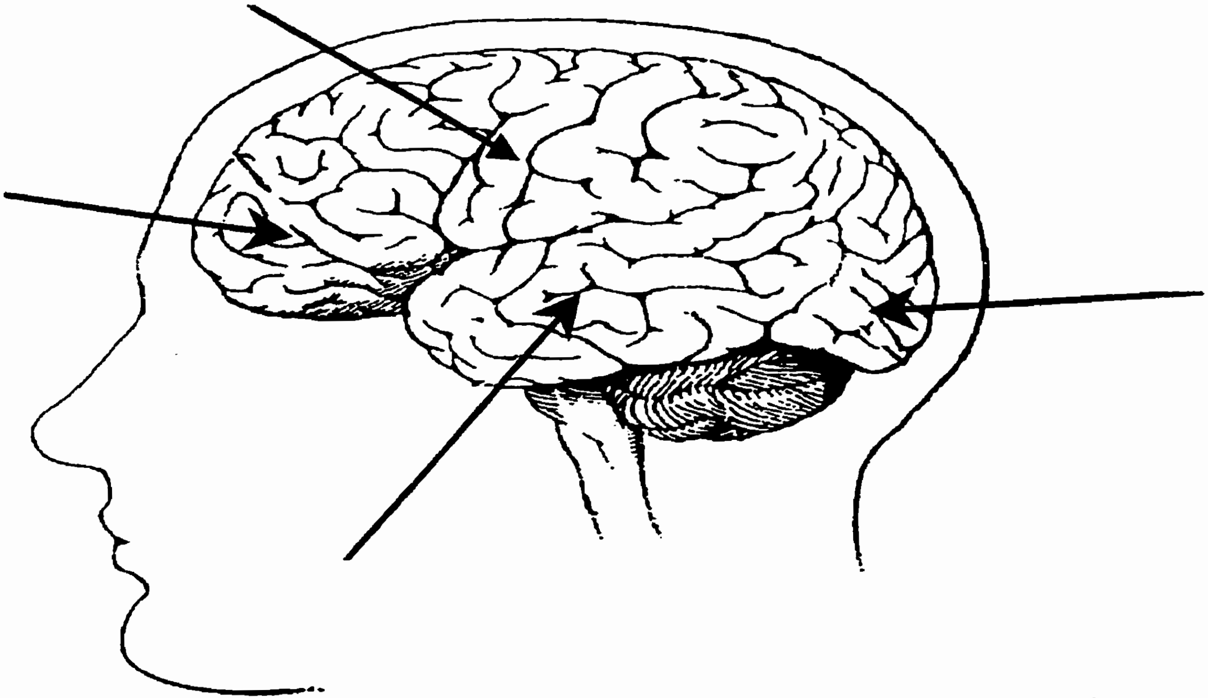


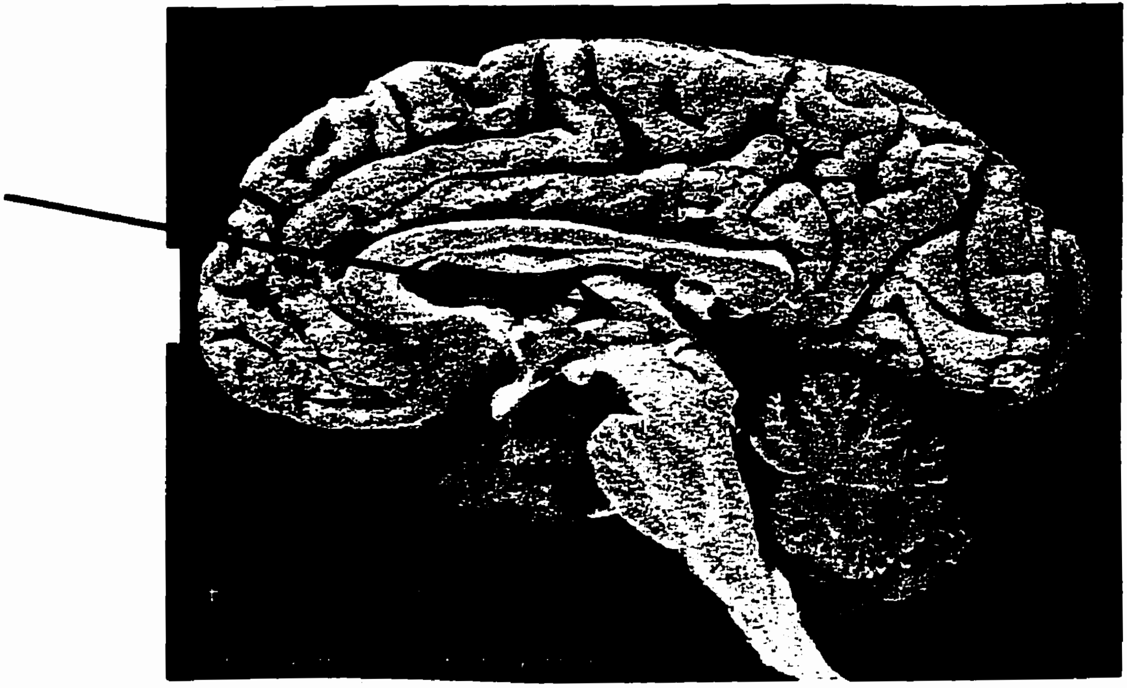
Overhead Reference 2.2





Handout 2.1
Parts of the Brain Affected by Alzheimer's Disease





Ask that while the participants are enjoying their refreshments during the break, to discuss examples of what abilities their residents have one day and not the next.

- BREAK - **20 minutes**

Experiencing Alzheimer's Disease 30 Minutes

Preparation:

- Sufficient photocopies of **Handout 2.2: Making Connections**
- 2 blank sheets of flip chart paper and regular markers
- Two 3x5 cards "Putting on shoes" written on one card, and
  "Brushing teeth" written on the other.
- 2 pairs of oven mitts, two pairs of glasses with Vaseline on the lens, a pair of shoes, a toothbrush and several cotton balls.

Facilitator Notes:

This activity builds on the information from the previous activities - knowing the parts of the brain, understanding its functions, and appreciating the complexity of message transfer. This is an experiential activity whereby learners will begin to understand the degrees of impairment that a person with Alzheimer's Disease experiences. The experience is intended to be confusing and to mimic some of the difficulties and problems a resident with Alzheimer's Disease might experience, as well as the difficulties a caregiver might have in providing instructions to such a resident

Method:

- Ask the learners to think about all the thoughts, movements, memories, understanding that go into an act as simple as drying the dishes.
- Give them 1-2 minutes to think about it.
- Pass out **Handout 2.2: Making Connections**
- Explain that these are some of the difficulties that someone with Alzheimer's Disease might experience during this simple task.
- Have a volunteer read each section.

- Divide the participants into two groups - A and B.
- Tell the groups that they are going to work on an activity that they do not want the other group to hear about.
- Give one group a card that has "putting on shoes" and the other group a card that has "brushing teeth" written on it.
- Give each group a piece of flip chart paper and markers and ask them to make up a list of things that they would say to a resident to show them how to do that task. Ask them to keep in mind what they know about the disease and how to communicate with someone with Alzheimer's Disease. Tell them to not allow the other group to hear or see what they write.
- Give each group 5 minutes to generate their list.
- Ask for a volunteer from each group. The volunteer from Group A will try to follow the instructions from Group B. The volunteer from Group B will try to follow the instructions from Group A.
- Put oven mitts, glasses with vaseline on the lens, and cotton batten in the ears of each volunteer. Put a pair of shoes near one volunteer and a toothbrush near the other volunteer.
- Group A and the volunteer from Group B will work in one part of the room. Group B and the volunteer from Group A will work in another part of the room.
- Both groups will give their instructions to their volunteer at the same time.
- Give both groups 5 minutes to complete their task or for their volunteer to give up. Encourage members of the group to help their volunteer as much as possible without actually doing the activity for them. Ask them to remember and use good communication skills.

- After 5 minutes have everyone sit quietly and think about what happened for one or two minutes. Then ask each volunteer to describe the difficulties or problems he/she had. Then ask the groups to talk about their difficulties of problems.
- Ask for comments and suggestions for resolving some of the problems and difficulties. Take at least 10 minutes for this discussion.

Handout 2.2: Making Connections

Based upon what you know now about the disease, imagine the problems you might encounter if you had Alzheimer's Disease and someone asked you to dry the dishes. The following is a list of things that you may not have thought of....

Thinking:

- You have damage in short term memory - you forget what was just said.
- You have damage in comprehension - you did not understand the words.
- You have partial damage in auditory processing - you only remembered part of the sentence. You only heard the word "dishes" in a sentence - so you get more dishes.
- You do not understand - you do not remember what the word "dishes" means.
- You misunderstand - you think dishes are windows - you dry the windows.
- You need a tea towel - you can not remember where it is or what it is.

Physically:

- You need to stand - your balance is affected so you have difficulty standing in one place.
- You need to pick up a towel - your fingers don't get the message from your brain.
- You need to straighten your arm toward the dish - your hand goes past the dish.
- You need to open your hand to grasp and pick up the dish - your fingers do not remember to keep holding the dish. It falls and breaks.
- You need to remember how to dry something - you only dry one side.
- You need to know what to do with the dish when it is dry - you hang onto it and will not let it go.
- You need to know to pick up another dish - you try to pick up another dish with a dish already in your hand.

- You need to remember that when the tea towel is wet, you get another - you refuse to let go of the towel.

Emotional:

- You think that the task is overwhelming - you start to cry.
- You remember drying dishes with your daughter and you miss her - you start to cry.
- You may be angry and frustrated at your inability to do something so easy - you throw the dish or the towel, or both.
- You may be embarrassed by your inability - you walk away by yourself.
- You may remember all the laughs that you used to have with your brother while you did dishes - you start to laugh to yourself.
- You used to sing while you did dishes - you start to sing.

Diagnostic Activity

25 minutes

Preparation:

- Photocopies of **Handout 2.3: Cognitive Capacity Screen Examination**
- Pens or pencils

Facilitator Notes:

This is an experiential activity that has two purposes. The first is to stress the importance of careful, comprehensive, ongoing diagnostic measures to determine whether someone has Alzheimer's Disease. The second is to give the caregiver a rudimentary understanding of the mental and emotional trauma of a person who must undergo such a test, especially when they are struggling with a degenerative mental disease and a possible diagnosis of Alzheimer's Disease. Doctors are advised to conduct a number of diagnostic tests in order to more accurately diagnose Alzheimer's Disease. These include:

Detailed History. Taking a detailed history given by someone who knows the person well. This history can reveal how the person has changed, what symptoms the person is having or other medical problems. The doctor should also perform a physical examination in order to reveal other health problems that can mimic Alzheimer's Disease or make the disease worse.

Blood Tests. The doctor should also order laboratory tests, which include a number of blood tests. A complete blood count (or CBC) can detect anaemia (or lack of red blood cells) or evidence of infections. Blood chemistry tests can check for liver and kidney problems, diabetes and a other conditions that can be treated.

Thyroid Studies. These studies evaluate the function of the thyroid gland, because when not functioning properly, it can produce a condition that appears similar to Alzheimer's Disease.

B_{12}. Vitamin B_{12} and folate level tests check for vitamin deficiencies. These deficiencies can produce symptoms similar to Alzheimer's Disease and can be successfully treated.

Venereal Disease. A test for venereal disease looks for syphilis which can cause a form of dementia. Penicillin can be used to successfully treat syphilis.

Electroencephalogram. The EEG records the electrical activity in the brain, including abnormal brain function. Although the test is painless, the wires that are attached to the scalp can be frightening for the person with Alzheimer's Disease.

Computerized Tomography. The CT scan is a kind of x-ray that takes a picture of the brain. The scan can detect strokes, abnormal pooling of blood, tumours and other conditions which can cause dementia The CT scan is painless but can be confusing for the person with Alzheimer's Disease, because they must lie quietly on a table while they are moved into a machine which surrounds them.

Magnetic Resonance Imaging. An MRI produces a picture like that of the CT scan. It uses magnetic energy rather than x-rays to produce a picture of the brain and is also a painless procedure. Doctors usually order CT scans as a first resort, and if they are not satisfied, they may subsequently order an MRI. CT scans are more readily available and less expensive, while MRI scans, which are much more expensive, are used to solve particular diagnostic questions.

Method:

- Tell the participants that they are going to give each other a test similar to one sometimes used by doctors to diagnose Alzheimer's Disease.
- Ask them to work with the partner they had for the icebreaker activity at the beginning of the session.

- Tell them that anything in brackets is <u>not</u> said to the person being tested. Tell not to help their partner with the answers.
- Tell the partners that they will switch roles in 7 minutes even if the testing of one person is not finished.
- After the learners have finished, ask them to discuss with each other how they felt about taking the test.
- Then in the large group, ask them how they think they would feel if they were 75 years old taking this test and knew they were experiencing some mental deterioration.
- Ask the group what other tests they think should be done before someone is diagnosed with Alzheimer's Disease.
- Using the Facilitator Notes, explain in basic terms other tests that can be done before a diagnosis of Alzheimer's Disease is given.
- Ask the group what points doctors should keep in mind when testing people who might have Alzheimer's Disease.

Handout 2.3: Cognitive Capacity Screening Examination

Instructions: Check items answered correctly. Write incorrect or unusual answers in space provided. If necessary, urge patient to complete the task.

Introduction to patient: "I would like to ask you a few questions. Some you will find very easy and others may be very hard. Just do your best."

1. What day of the week is this? ____________
2. What month is this? ____________
3. What day of the month is this? ____________
4. What year is this? ____________
5. What place is this? ____________
6. Repeat these numbers: 8 7 2 ____________
7. Say them backwards: ____________
8. Repeat these numbers: 6 3 7 1 ____________
9. Listen to these numbers: 6 9 4.
   Count from 1 to 10 out loud,
   then repeat 6 9 4. ____________
10. Listen to these numbers:
    8 1 4 3. Count from 1 to 10
    out loud, then repeat 8 1 4 3. ____________
11. Beginning with Sunday, say the
    days of the week backwards. ____________
12. 9 + 3 is: ____________
13. Add 6 to the previous answer (or "add 6") ____________
14. Take away 5 from the previous answer or
    ("take away 5"). ____________

Repeat these words after me and
remember them.

I will ask for them later:

HAT CAR TREE TWENTY-SIX

15. The opposite of fast is slow.
The opposite of up is: __________
16. The opposite of large is: __________
17. The opposite of hard is: __________
18. An orange and a banana are both
fruits. Red and blue are both: __________
19. A penny and a dime are both: __________
20. What were those words I
asked you to remember? (HAT) __________
21. (CAR)
22. (TREE) __________
23. (TWENTY-SIX) __________
24. Take 7 from 100. (93) __________
25. Then take away 7 from what is
left and keep going. (86) __________
26. Minus 7 (79)
27. Minus 7 (72) __________
28. Minus 7 (65) __________
29. Minus 7 (58) __________
30. Minus 7 (51)

TOTAL CORRECT (maximum score is 30) __________

If the patient has a high school education, a score of **less than 24** generally indicates impaired intellectual functions.

Source of test: Cognitive capacity screening examination (Adapted from Jacobs, et al., by Hamdy, R., Turnbull, J., Norman, L., and Lancaster, M. (1990). *Alzheimer's Disease: A Handbook for Caregivers.* Baltimore, MD: C.V.Mosby.

The Causes of Alzheimer's Disease - A Crossword Puzzle

10 minutes

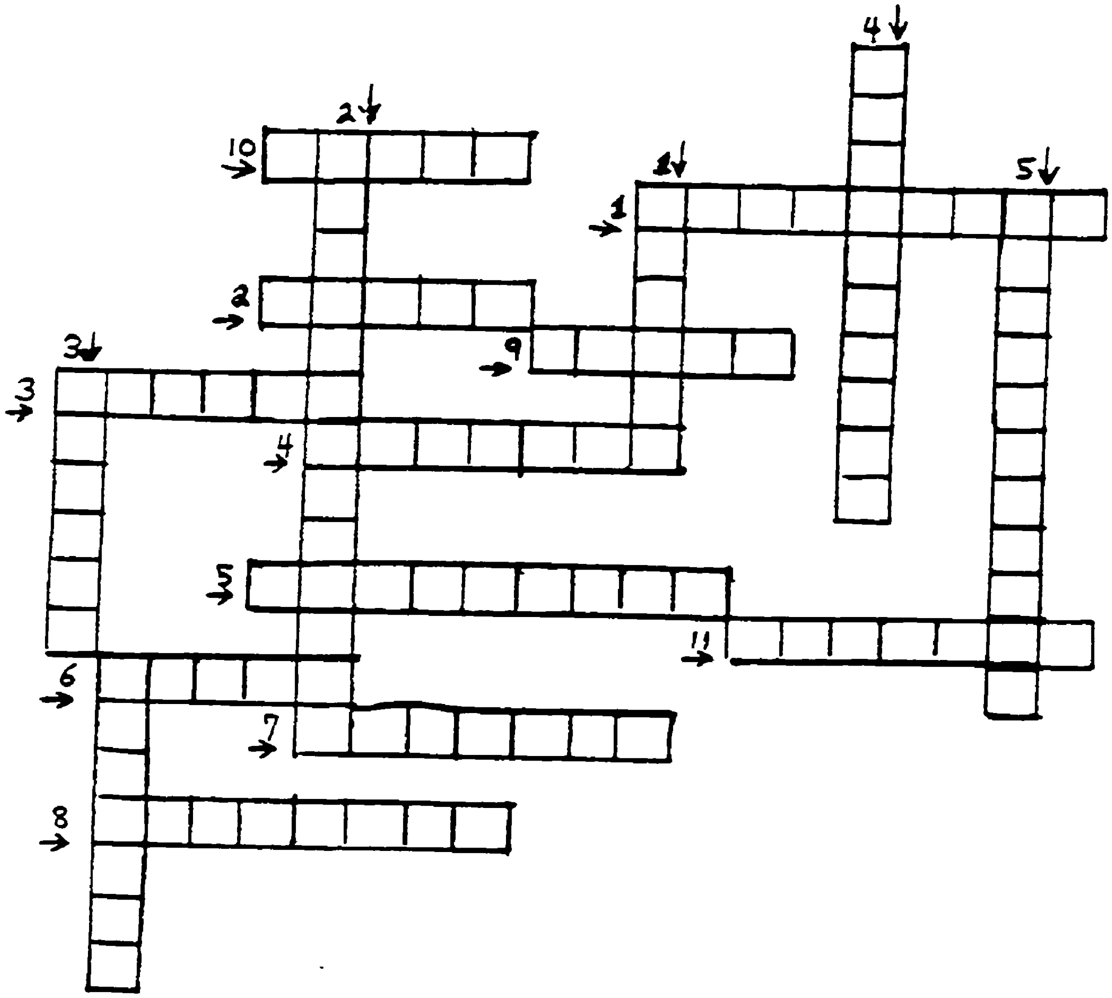
Preparation:

- Overhead projector and screen set up
- **Overhead 2.3: The Puzzle**
- Sufficient photocopies of **Handout 2.4: The Puzzle** for the participants.
- Sufficient photocopies of **Handout 2.5: The Clues**
- **Overhead 2.4**: **The Completed Puzzle**

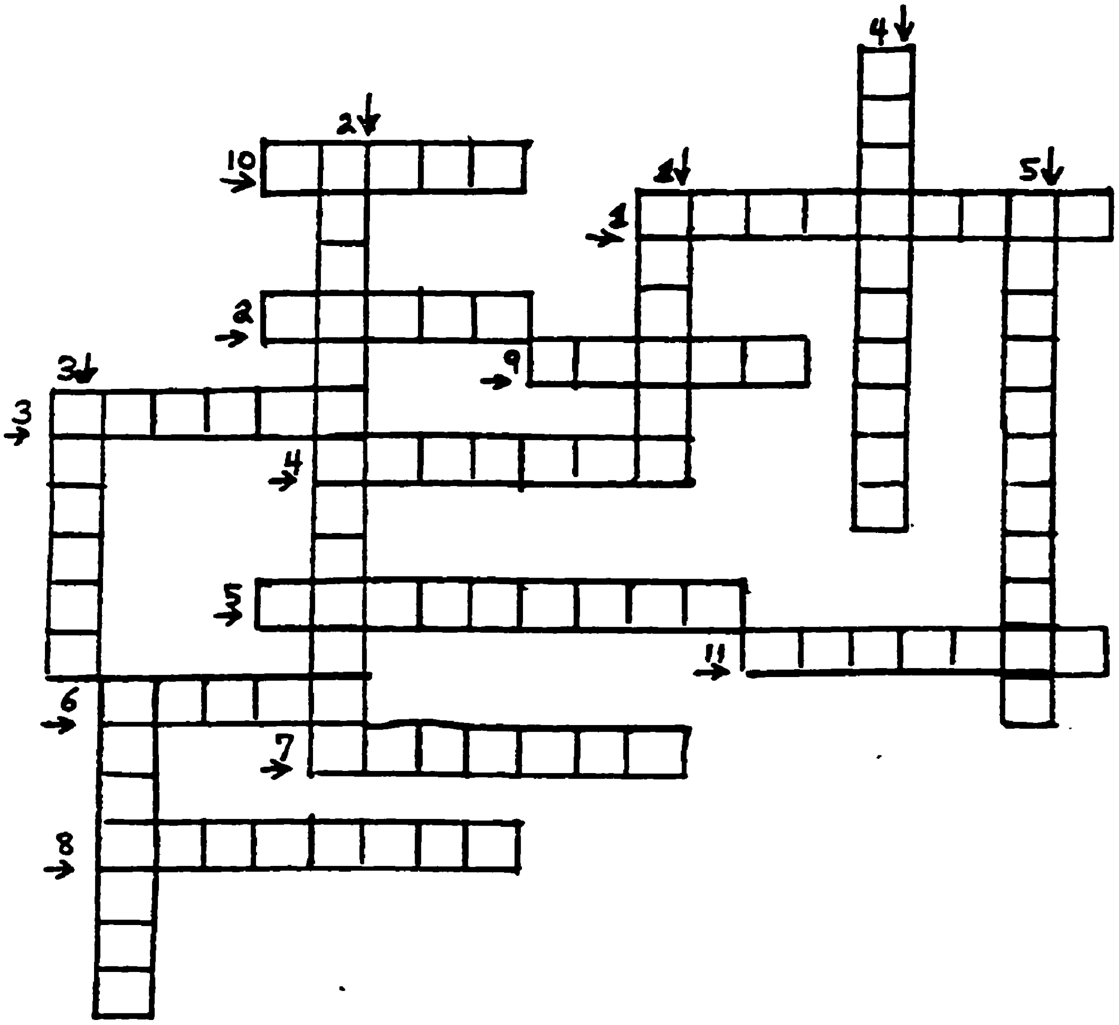
Method:

- Tell the participants that there are several theories and many myths about the causes of Alzheimer's Disease. To date the causes for Alzheimer's Disease are not known. Research tells us that there are probably several factors that cause Alzheimer's Disease.
- Put up **Overhead 2.3: The Puzzle.**
- Distribute **Handout 2.4: The Puzzle**
- Distribute **Handout 2.5: The Clues**
- Tell the learners that they may work with a partner to complete the crossword.
- When everyone has finished, or after 7 minutes have passed, put up **Overhead 2.5: The Completed Puzzle.**
- Spend two minutes reviewing the answers to the crossword.

Overhead 2.4: The Puzzle



Handout 2.4
The Puzzle



Handout 2.5: The Clues

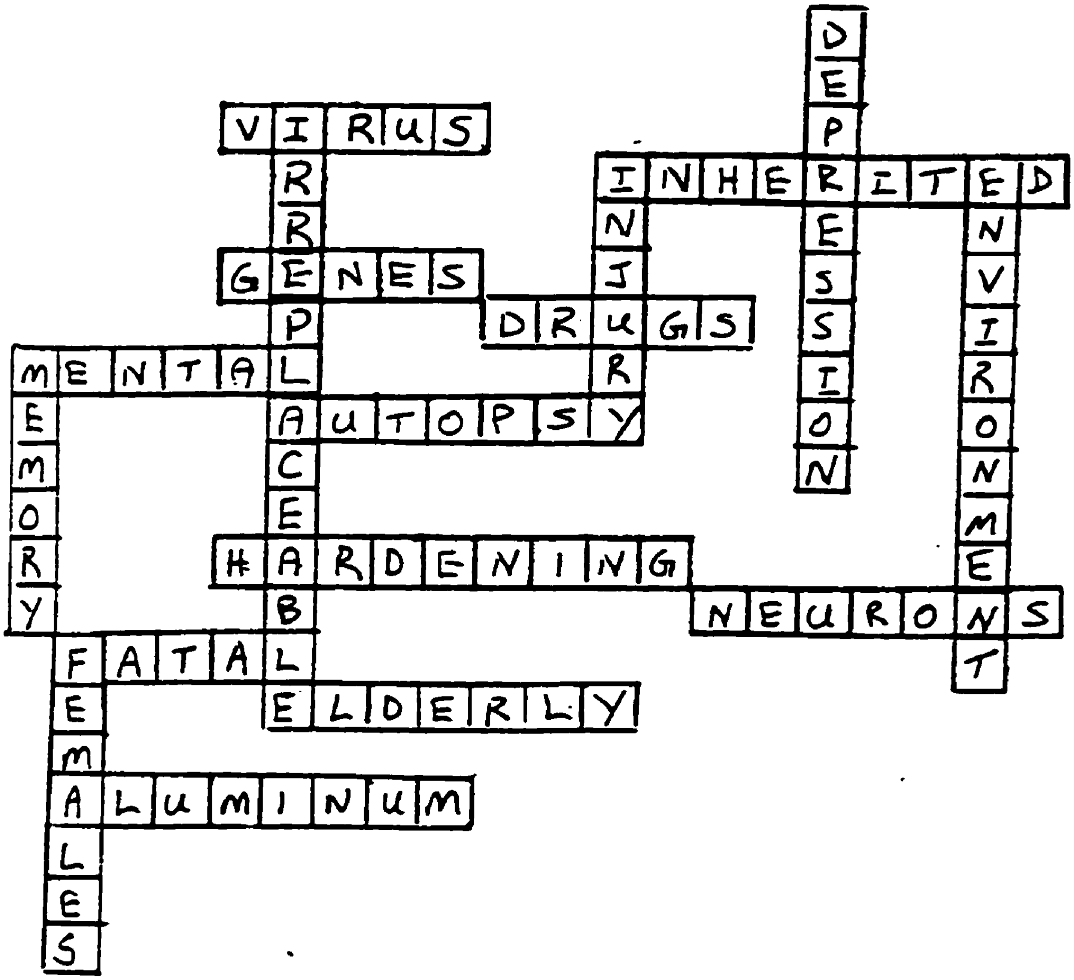
Across:

1. Small percentage passed down in families.
2. We all wear these but we inherit them too
3. Having Alzheimer's Disease is a m_____ and physical challenge.
4. Alzheimer's Disease can now be diagnosed with up to 95% accuracy. Formerly, it could only be definitively diagnosed with an _______ (dissection and examination after death).
5. Alzheimer's Disease is not when you have a thickening in your arteries.
6. Alzheimer's Disease always ends in death, it is called a _____ disease.
7. Alzheimer's Disease affects mostly the _______ age group.
8. It is a myth that this substance that some pots are made out of causes Alzheimer's Disease.
9. There isn't one of these to cure or protect against Alzheimer's Disease.
10. Some say that a v _____ may cause Alzheimer's Disease.

Down:

1. Some say that a severe head _____ might be a cause for Alzheimer's Disease.
2. Recently, scientists have discovered that brain cells can be made over again. Formerly they were thought to be ir ______.
3. Alzheimer's Disease affects the place that stores our past.
4. A deep sadness, described as _________, frequently accompanies Alzheimer's Disease in its early stages.
5. Some say that there is something in our surroundings that may cause Alzheimer's Disease.
6. There are more of these who have Alzheimer's Disease, but men get Alzheimer's Disease too. However, men die sooner from other causes.

Overhead 2.4
The Completed Puzzle



Observing Behaviours Associated with Alzheimer's Disease

25 minutes

Preparation:

- Overhead projector and screen set up
- Sufficient photocopies of **Handout 2.6: Strengths and Challenges for Individuals with Alzheimer's Disease**
- Flip chart paper and markers

Facilitator Notes:

This activity has two purposes: First, to promote the participants' abilities to describe some behaviours that are typical of people with Alzheimer's Disease. Second, to attempt to refocus the participants' thoughts away from what those with Alzheimer's Disease cannot do, toward what they are still capable of doing.

Method:

- Ask participants with more than two years experience caring for those with Alzheimer's Disease to raise their hands.
- Organize pairs so that an experienced caregiver is teamed with one who is less experienced. If everyone has more than two years experience, keep the same partners as were used in the Diagnostic Testing activity.
- Tell everyone to work with their partner to describe some typical behaviours associated with Alzheimer's Disease. On a sheet of paper, they are to list the behaviours under two columns, one headed "CAN DO" and the other headed "HAS DIFFICULTY."
- Give the pairs seven minutes to list their descriptions.

- Ask each group to read one item from their CAN DO list while a volunteer records all items on flip chart paper. Get one response from each pair and go around the room again until all the behaviours have been recorded.
- Repeat with the HAS DIFFICULTY list.
- After the groups have finished recording, ask them to compare the flip chart list with their own list. Ask the participants whether they focused more on the "CAN DO list or the "HAS DIFFICULTY" list. Which list was longer? Which list was more descriptive?
- Pass out **Handout 2.6 Strengths and Challenges for Individuals with Alzheimer's Disease.**
- Ask participants to compare their list and the flip chart list with their handout.
- Ask the large group to suggest ways to rethink some of their HAS DIFFICULTY descriptions to more positively refocus on what people with Alzheimer's Disease can do.

Flip chart 2.2
Can Do / Has Difficulty

Can Do	Has Difficulty

Handout 2.6 Strengths and Challenges of Individuals with Alzheimer's Disease

The following is a list of typical abilities and disabilities that occur in persons with Alzheimer's Disease.

THE PERSON "CAN DO"

- can remember events that happened a long time ago.
- remember how to go to the bathroom.
- follow simple directions.
- love and be loved.
- touch and be touched in a friendly, non-threatening way.
- find humour in funny things and has a sense of humour.
- enjoy dancing, singing and music.
- walk for great distances.
- perform many acts of daily living with guidance and patience
- laugh and smile
- can remember many hymns and prayers
- work at familiar simple tasks
- remember parts of tasks
- remember bits of pieces of more recent events
- remember names and functions of things from long ago
- repeat a task over and over again
- make themselves understood without the use of spoken language
- can eat while walking
- respond kindly and patiently with small children
- enjoy dogs, cats and other pets
- give vivid descriptions of real or unreal situations
- go great lengths of time with little sleep

THE PERSON "HAS DIFFICULTY"

- being ignored
- remembering people's names.
- reading, writing and understanding what has been read.
- with some body movements.
- reacting to situations that they have little control over

Reflections 8 minutes

Preparation:

- Sufficient photocopies of **Handout 2.7: Reflections**
- Cassette tape of quiet music
- Cassette Player

Facilitator Notes:

This is an opportunity for the learners to put together what they have learned about Alzheimer's Disease. Encourage the learners to write as much as they wish.

Method:

- Tell the learners that they have an opportunity now to write about what they have learned and what it means to them.
- Tell them that this is their homework for the next session.
- Ask them to please bring their "Reflections" to the next session.
- Give them ten minutes or the time remaining to start the activity.

➢ **Sincerely and earnestly, thank them for coming.**

Handout 2.7: Reflections

I have discovered that residents with Alzheimer's Disease can do...

I learned that the parts of the brain most affected by Alzheimer's Disease are ...

Five behaviours that a resident may demonstrate that tell me that this person may have Alzheimer's disease?

1. ____
2. ____
3. ____
4. ____
5. ____

One thing that I did not understand today was ...

Choose one incident that happened this week that shows how I am more aware of the effects of Alzheimer's Disease on one of my residents. Describe this incident on the back of this page and bring it with you for the next session.

MODULE III:

STRESS IN THE WORKPLACE

Time Required

- 180 minutes
- 20 minute break included

Facilitator Preparation - General

✓ Flip chart, paper, masking tape, markers – paper and dry erase or water soluble markers.

✓ Sufficient number of copies of Module III Handouts 3.1 and 3.2

✓ Tape player and quiet music cassette

✓ Overhead Projector and Module III Overhead 3.1

✓ Extra writing materials (pens and paper)

✓ Post-it Notes (two pads)

✓ Optional: One 'squish' ball (soft 2 inch pliable balls) for each table of participants to relieve stress throughout session

✓ Optional: Bag of Hard Candies used as condiments (to be evenly distributed amongst learners' tables)

Welcome Back! **5 minutes**

Preparation:

None

Method:

- Welcome back the participants and express pleasure that they have returned for this session.
- Tell them that they will have a chance:
  - ✓ to practice what they have learned about Alzheimer's Disease,
  - ✓ to use what they have learned from the last two sessions,
  - ✓ to learn about coping with stress during this session.
- Tell them that, if they want to, they will have the opportunity to share their reflections from the last session with the group.

Icebreaker- ABCs

10 minutes

Preparation:

None

Facilitator Notes:

The most important aspect of this activity is for the participants to have fun. By doing so, they will realize that their enjoyment is contagious. A module on the topic of stress can easily become a reason to gripe, complain and become depressed. These are all highly contagious negative behaviours. This activity serves to illustrate that the opposite is also true.

Method:

- Divide the group in half.
- Ask each group to take one sheet of flip chart paper and write the alphabet from A to Z down the left-hand side of the page.
- Tell the group that they are to find one object that begins with each of these letters. These objects need to be something that one of the participants in the group is wearing or carrying. Once the object is found, it must be put on the table in front of them.
- Whichever team completes the alphabet first or whichever team has the most plausible items at the end of 5 minutes wins.
- The winning team must then read through the alphabet and hold up each article as the appropriate letter is read.
- Ask the group how it felt to do the activity and why they did it the way they did.

Agenda

2 minutes

Preparation:

- Prepare a flip chart page ahead of time showing the Agenda (**Flip chart 3.1: Agenda**).
- Post the Agenda in a prominent place in the room using masking tape and leave it up for the duration of the session.

Method:

- Go over the agenda, mentioning that most of the time will be spent on:
  - ✓ Getting to know what stress is
  - ✓ Understanding that people react to stress in different ways
  - ✓ Realizing that caregivers' reactions to stress can affect residents
  - ✓ Finding ways to lower negative stress levels
- Add that the group may not complete all items on the agenda.
- Tell the learners that the group will take time to discuss the important issues.

Flip chart 3.1: Agenda

Welcome Back	2 minutes
Icebreaker- ABCs	10 minutes
Agenda	2 minutes
Discussion Topics	3 minutes
Reflection Review	15 minutes
Sources of Stress	35 minutes
Reactions to Stress	40 minutes
- BREAK -	20 minutes
Stress Relief Demonstrated	40 minutes
Reflections	8 minutes

Discussion Topics

3 minutes

Preparation:

- Overhead projector and screen
- Copy of **Overhead 3.1: Discussion Topics for Module III**

Method:

- Put up **Overhead 3.1: Discussion Topics for Module III**
- State that during this session we will talk about:
  - ✓ Knowing what stress is
  - ✓ Understanding how we react to stress
  - ✓ Realizing that caregivers' reactions to stress can affect residents
  - ✓ Learning ways to lower negative stress levels

Overhead 3.1:

Discussion Topics for Module III

- ✓ Knowing what stress is
- ✓ Understanding how we react to stress
- ✓ Realizing that caregivers' reactions to stress can affect residents
- ✓ Learning ways to lower negative stress levels

Reflections Review

15 minutes

Preparation:

Extra copies of **'Reflections'** from last session.

Facilitator Notes:

Emphasize that sharing notes or thoughts from their **Reflections**, although very beneficial for all, are personal choices.

Use the time judiciously. Try to incorporate the reflections of as many participants as possible. If the participants have trouble sharing, do not belabour the issue. Move on to the new material. On the other hand, if discussions have overrun the time allotted, try and draw conclusions before moving on to the new material.

Method:

- Ask participants to take out their **Reflections** from last session.
- State that you are going to ask them to share their thoughts from their reflections. Tell them that there are no wrong answers and that they are free to talk about their own experiences or to add to others' experiences.
- Tell them that they can share if they want to, but they do not have to.
- Ask them to talk about the incident they wrote about in their reflection.
- Give participants time to answer and be encouraging to everyone.

Sources of Stress **40 minutes**

Preparation:

- Flip chart, paper, and markers
- Four pieces of flip chart paper taped to a place where they can be easily seen and written on. Each piece of flip chart paper should have a separate heading: Resident related, Management related, Co-worker related, and Family Member of resident related.
- Masking Tape

Facilitator Notes:

The first part of the module's activities asks the learners to identify sources of stress. The facilitator must make every effort to ensure that this process doesn't turn into a negative gripe session. Grouping stress into areas of concern is an effort meant to gain distance and objectivity from problems so that caregivers can begin to think rationally about their reaction. The avoidance of personal pronouns also attempts to make the process less personal.

Next, learners are asked to generate possible solutions to their sources of stress. This process gives a sense of control over the stress response. Finally, participants learn about a variety of ways to cope with stress and experience an appropriate activity to relieve stress.

Use the following reference notes. Do not read the facilitator notes to the learners; use them to develop your brief talk about stress.

Facilitator Reference Notes: The Role of Stress in Everyday Life

The term stress is as misused as it is over-used in today's language. The commonplace reference and the actual meaning of stress are quite different. The following notes attempt to summarize what stress is and how we interpret it in our everyday life.

Stress is a biological response rooted in human evolution. When the human body responds to a threat, certain physical reactions occur called the "fight or flight" response. When an individual perceives the presence of a threat, the hormone system responds by preparing the body to fight or run away. Blood flow, blood pressure and breathing increase. Mental functions increase and the senses are enhanced. The muscles which move the body in the arms, legs and torso work more efficiently. The immediate responses work to preserve our body in the face of danger. If the threat is not immediately resolved, the stress response may go on too long resulting in confusion, high blood pressure and muscle tension.

Stress is not altogether a bad thing. Some stress is very healthy for our body. When the perceived threat is successfully handles, the resulting relief is perceived positively. The resulting positive effects help transmit memories from short term to long term storage and elevate mood

If the initial stress response is perceived negatively (e.g., I shouldn't feel this way, I should have done something different), emotions such as fear, anxiety, and anger cause the body additional stress which is called distress. When distress is experienced over a long period of time, especially when the person has little control over outcomes, the result can be a variety of health concerns such as depression, anxiety, an inability to concentrate, high blood pressure, poor breathing (e.g. asthma), and muscle tension which reduces joint mobility.

Skills for coping with stress are developed on the basis of individual experience. Successful coping skills are based on the individual's ability to accurately perceive the nature of the initial threat and to mentally control their stress response through recognizing it, understanding the potential outcomes of distressed behaviour, developing a social support system to counteract stress, and learning appropriate ways to release stressful feelings and tensions.

Method:

- Refer to the facilitator notes on stress to expand on the following main points.
- Tell the learners that there are 3 parts to stress:
  - ✓ First there are all the things that happen every day that can lead to stress – everything from a daughter going out on her first babysitting job to a resident hitting and swearing on the way to a bath. Some stress is chronic, in that related events happen frequently over long periods of time. Other stress is a response to a relatively isolated incident or episode.
  - ✓ The second part of being stressed is deciding how to feel about the stress. We can choose to ignore some events and episodes and they "roll off our back" or we can choose to become upset. Whatever upsets us and is not ignored can intensify our stress responses.
  - ✓ What actions we take as a result of this choice determine how much we feel pressured and 'stressed out'.
- Ask the participants to find a new partner, someone with whom they have not worked before.

- Ask them to think about work and make up a list of things that happen that cause them stress. Ask them to write these down under one of four headings:
  - ✓ Resident related
  - ✓ Management related
  - ✓ Co-worker related
  - ✓ Residents' family member related
- Tell participants to avoid using personal references to specific other persons. For example, they should not say "Mrs. T. constantly follows me around," but rather say "A resident constantly follows staff around."
- Give the learners 15 minutes to generate their lists.
- Ask each pair to report their stresses related to Resident related stress. Go around the room until all items are recorded. Ask a volunteer to record responses on a prepared flip chart with the heading "Resident related." Make sure to capture repeated responses by tallying numbers in brackets after the responses. (x3, x4 and so on)
- Repeat with the other three headings.
- Ask the whole group to consider whether the itmes on each list are:
  - ✓ Repetitive (chronic) or episodic (happens once)
  - ✓ Solvable or apparently unsolvable
  - ✓ Controlled by someone else or controlled by oneself

Reactions to Stress

40 minutes

Preparation:

- Flip chart paper, markers
- masking tape
- Post-it Notes – at least two pads
- Flip chart paper responses from **Sources of Stress** activity

Facilitator Notes:

This activity builds upon the results of the previous activity: **Sources of Stress**. It is a two part activity. In the first part, participants will brainstorm to generate a list of many possible alternative responses to the event or condition listed – both appropriate and not. The idea is to access how caregivers actually react to stressful situations. In the second part, the participants will evaluate how effective some of their reactions actually are. The aim is to uncover positive strategies that some caregivers are already using in their facilities.

Method:

- Tell the participants that they are going to use their flip chart paper responses from the Sources of Stress activity to complete the next activity. Carefully, take the flip charts down from the wall.
- Divide the group in half and give each group two of the four flip chart lists completed in the previous activity.
- Ask each group to think of all their possible reactions to each particular stress that has been listed on their flip chart lists.

Example:	Reactions
Resident related stress "A resident constantly follows staff around."	- avoid resident - tell the resident to leave staff alone - ask the resident to help push things or carry things, etc.

- Have the groups either write directly on the flip chart paper or use Post- it Notes and attach them to the flip chart paper. Give them 10 minutes to do as many of the items on their lists as possible. When they have finished, tape their flip chart paper to walls where they are easily seen.
- Have a spokesperson from each group describe the reactions they have written down for one list. Arrange for a different spokesperson for each list.
- As discussion proceeds, generate a list, on flip chart paper, of the most effective responses. Title this flip chart page: Effective Responses
- In the large group, work through each list and decide which reactions will actually decrease their stress level and explain why. Decide which responses will increase their stress level and eliminate them by crossing them out with a marker.
- Continue the process with each category until all positive responses have been discussed and recorded on the Effective Responses list.

During the break time ask the participants to talk about ways that they deal with stress at work and at home.

- BREAK - **20 minutes**

- Following the break, take 5 minutes to discuss how the most effective responses could be characterized.

Stress Relief Demonstrated **40 minutes**

Preparation:

- Photocopies of **Handout 3.1: Ways to Relieve Stress at Work**
- Cassette tape of quiet relaxing music
- Prepared flip chart questions – **Flip chart 3.2: Relaxation Questions**

Facilitator Notes:

The aim of this activity to present and discuss a number of alternatives to stress relief that participants may not have thought of and to participate in a simple relaxation activity.

Prepare for the relaxation activity by reading it aloud to yourself several times, with a soothing musical background, until you have found a good pace and tone of voice.

Method:

- Pass out **Handout 3.1: Ways to Relieve Stress at Work**
- Have a volunteer read through each of the six descriptions in Handout 3.1.
- Ask the participants to circle the headings listed on their handout that appeal to them or that they currently use.As each description is read ask the participants for questions or comments.
- Ask those who use a particular method to talk about their experience, and their success or failure with it. After all the alternative methods have been read and discussed, give the participants five minutes to talk with their neighbours about methods that they would like to try or give

them the opportunity to talk with those who are already practitioners of a particular method. Invite the group to get up and move around to talk with others in the group.

- After five minutes, ask the group for their attention and tell them that they are now going to participate in a relaxation activity.
- Start a music cassette tape with quiet, relaxing music – quiet water sounds are excellent.
- Ask them to find the most comfortable position that they can in their chairs or, if they feel comfortable doing it, to lie flat on their backs on the floor. Tell them to close their eyes, listen carefully and follow the directions. Then read the following script, slowly and quietly, remembering to use expression and appropriate pauses.

Calm your thoughts and listen to my voice. Breathe in through your nose and out through your mouth. When you breathe in count to three and when you breathe out count to three. Ready. Breathe in: two, three. Breathe out: two, three. Breathe in: two, three. Out: two, three. Again, breathe in: two, three. Out: two, three. Keep breathing this way while you listen to my voice.

Now, when I ask you, I would like you to contract or squeeze your muscles as hard as you can while I count to 10. When I get to ten, I would like you to <u>completely</u> relax those muscles that you were contracting.

Good. Now when I ask you, I would like you to contract all the muscles in the toes in your feet. Scrunch them up as hard as you can and hold, hold, hold this position while I count to ten. Ready. Contract: One..., two..., three..., four..., five..., six..., seven..., eight..., nine..., ten.... Now, let the muscles relax..., let all the

tension go from your toes..., let it go..., let it go..., and relax all your toes. Feel all the tension slip away from your feet....

Now I want you to think about contracting the muscles in your calves. When I ask, I want you to contract those muscles. Ready? Contract. Squeeze, squeeze, squeeze those muscles while I count to ten. One...,two..., three..., four..., five..., six..., seven..., eight..., nine..., ten... Good, now let those muscles relax, relax, relax, feel all the stress leave those muscles, let them feel that they are floating free.

Now, I would like you to think about contracting the muscles in your bum. When I ask you to, squeeze these muscles together as hard as you can. Ready and squeeze. One..., two..., three..., four..., five..., six..., seven..., eight..., nine..., ten.... Good, now relax, relax, relax, Let the muscles go, feel all the tightness slip out of those muscles.

Now, I want you to think about contracting all the muscles in your stomach. Remember to think about your breathing: ...in through the nose and out through the mouth. Ready. Contract your stomach muscles. One..., two..., three..., four..., five..., six..., seven..., eight..., nine..., ten.... Good, now relax..., relax..., relax... Let the muscles go, feel all the tightness slip out of those muscles....

You are doing very well and now I want you to continue but remember to slowly and calmly keep breathing in through the nose and out through the mouth. Now, I would like you to think about making a fist and squeezing your fists using both hands as hard as you can. Ready? Now, squeeze. One..., two..., three..., four..., five..., six..., seven..., eight..., nine..., ten.... Now slowly,

**open your fist while I count to five. Go slowly and by the count of five, have your fist fully relaxed. One…, feel the tensions slipping, two…, three…, feel your fingers relax, relax four…,
five.**

Now I would like you to squeeze your shoulder blades together as hard as you can. Keep breathing slowly and rhythmically while you contract your muscles. Ready and squeeze. One…, two…, three…, four…, five…, six…, seven…, eight…, nine…, ten…. Now relax your shoulders slowly and completely. Let all the tension and tightness slip away.

Now I want you to tighten your jaw and face muscles. Imagine scrunching your face into a little ball while I count to ten. Ready, scrunch - One…, two…, three…, four…, five…, six…, seven…, eight…, nine…, ten…. Now relax your face and jaw muscles, imagine the stress floating away upwards.

You have done a wonderful job and I would now like you to squeeze some muscles together all at once. When I ask you to I would like you to squeeze your ankles, legs, bum, stomach, back, hands and arms together all together. Is everyone ready? Now squeeze. Hold everything together. One…, two…, three…, four…, five…, six…, seven…, eight…, nine…, ten….

Now slowly let everything go. Relax…, relax…, relax…, relax. … Feel the wonderful weightlessness, the relaxation, the calm. Now, think about your breathing. In…, out…, In…, Out…, In…, Out…, In…, Out…

I want you to concentrate on just your breathing for a while.

(silence for 1 minute)

Now, I am going to count to five. When I reach five, I want you to slowly open your eyes. Ready... One, Two, Three, Four, Five.

Think about how you feel right now.
Think about the areas of your body that felt the best after contracting and relaxing the muscles in that part.

- Give 30 seconds for quiet, individual thought.
- When you are ready ask the learners to slowly get up and rejoin everyone at the table.
- If needed, awaken those around you who have fallen asleep by gently rubbing their arms.
- When you have everyone's attention again, ask them to discuss with their neighbour how they felt about this particular exercise. Give the participants two minutes for discussion.
- Now ask them, as a large group discussion, the questions posed on Flip chart 3.2.
- Tell the participants that when they have ten minutes, they can follow the same procedure at home, during their coffee or lunch breaks to relax and de-stress themselves.
- Also mention that some people take just a few minutes to concentrate their relaxation technique on just one or two parts of their body thereby allowing them to use the technique anytime, anywhere throughout their working day.
- Summarize this activity by referring the participants back to the handout and telling the learners that they now have a number of ways to lower their stress level. Tell them that they now have the tools but they must remember to use them.

Flip chart 3.2: Relaxation Questions

- How did you feel at the end of this activity?
- Is there one area of your body that feels more relaxed than others?
- Where do you "hold stress?"
  - ✓ When you notice that one particular area seems to hold stress more than another, concentrate on relieving that stress when an opportunity presents itself. For example, many people need to tighten and relax their shoulders throughout the day, because that is where they retain most of their stress.
- Are there other areas that you could have worked more fully?

Handout 3.1: Ways to Relieve Stress At Work

Stress Relief is personal work. Each of us, unconsciously or not, use a variety of ways to calm ourselves. The following are a few strategies that some people use very successfully to cope with stressful situations at work.

Make a Friend

Many facilities `partner' newcomers for a good reason. Finding your way in a new and difficult environment is very stressful. However, having just one friend who is in a similar situation eases stress substantially. Being able to ask questions of each other, sharing fears, and being encouraging to one another are great ways to relieve stress. Sometimes, sharing stress relief with a friend at work means just a shared coffee break, a meaningful smile, or a comforting arm around a shoulder

Others develop a friendship with someone whom they already know at the facility, or choose to make friends with someone whose work habits they admire. Some may make a friend who is experienced and willing to share their knowledge and act as a mentor for a newcomer.

> ***"All I had to do was see her in the hall for a few seconds. She had been around a long time and she just knew when I had had the biscuit. She would put her hand on my arm as she went by and give it a little shake. I knew then, that my load was just a little lighter that day."***

Keep Your Sense of Humour - or Find One

Caring for those with Alzheimer's Disease is very stressful work. Sometimes the work is hard, often thankless, and frequently hectic. Whether the work makes you miserable or makes you happy is often a personal choice, or an act of will. It requires an **active search** to find the happy, funny or joyful parts of the day – the events that make your day a better one. At the very least, on a lunch break or on the way home from work, concentrate on or find the one happy situation or incident that happened at work. Forget the rest.

> ***"The inspectors had just walked through the door of the lobby and were walking toward us. There are lots of those fake trees in the lobby. I had Mr.D ...and I had planned on taking him out for a walk. I had turned to him to tell him that he was looking pretty spiffy. Before I knew what happened, he had pulled it out and peed on one of those trees."***

Smile

Smile at the people you work with and smile at the people you care for. Smiling is contagious. The muscles we use to smile also send calming impulses to the brain. You tend to smile more when you are happy and relaxed. And the more you smile the more calming messages are sent to the brain.

Smiles also work to send messages to other people that you are happy. For most of us, seeing a happy face simply makes us happier too, or at least it arouses our curiosity about what is causing such happiness.

> ***"Sometimes when I come to work I feel a lot more like crying than smiling. But when I walk through that door and see Mrs. D...smiling at me 'cause I am coming on shift...Well, it doesn't take long after that for me to start sharing smiles of my own."***

Getting Away when you are at Work

Many caregivers report the need for some mental and physical space while at work. The greater the stress throughout the day, the greater the need for some distance. Some caregivers choose to go for a walk while on their breaks, others opt to go to their car for some peace and quiet, while others seek out the chapel in their facility, if they have one. Caregivers, giving constantly of themselves to their residents' needs, require breaks throughout the day to care for themselves and their sense of well-being.

> ***"When I just can't stand it anymore, I go and stand in the broom closet just for a few minutes. I know that it sounds crazy, but it is dark and quiet in there and there isn't anywhere else that is, so I just go in there and close my eyes for a few minutes, take a few breaths and then I am ready to go again"***

Write

Caregivers do not often take the time to write their stresses or troubles down on paper. Take the time to make a list of what is good about what you have done today and what is going badly. Often, without realizing it, many people allow a short list of what has gone wrong to ruin a long list of what has gone well. On those days when the 'what's wrong' list is longer, just going through the actions of getting it all down on paper acts as a way to relieve stress. When all the items have been listed, choose one that can be acted upon and do something about it.

> ***"Funny, how you can be thinking that you are having such a rotten day, but when I finally get it down on paper, I realize that just one little thing has been bugging me all day."***

Self-Talk

If no one is telling you what a great job you are doing, then tell yourself. Caregivers report that they never hear about the good work that they do, just the bad things that happen. Administrators point out that that is probably true. Inspectors and families call administrators who in turn go to caregivers when difficulties arise. When caregivers do not receive any thanks or appreciation from the residents, and hear only about complaints from superiors, they absolutely need to tell themselves that they are good, kind, worthwhile, hardworking people.

The message that caregivers give themselves, often unconsciously, is a repeat of what others have told them: "slow, dumb, and stupid." It takes a conscious effort to say, repeat and mean statements like: "I am doing as good a job as I can," "I am a good person," " I am the only one who can give Mary a bath without her getting upset."

> ***"All the staff think that I am crazy when I talk to myself. But, I tell myself, out loud, what a good job I am doing. Pretty soon I'm doing a good job and I feel pretty good about it. When they ask me what I am doing, I tell them I'm praying and in a way, I guess, I am."***

Reflections **8 minutes**

Preparation:

- Photocopies of **Handout 2.6: Reflections**
- Cassette tape of quiet music
- Cassette Player

Facilitator Notes:

This is an opportunity for the learners to put together what they have learned about stress and themselves. Encourage the learners to write as much as they wish.

Method:

- Tell the learners that they have an opportunity now to write about what they have learned and what it means to them.
- Tell them that this is their homework for the next session.
- Ask them to please bring their "Reflections" to the next session.
- Give them ten minutes or the time remaining.

➢ **Sincerely and earnestly, thank them for coming.**

Handout 3.2: Reflections

What did I learn about how I handle stress?

What are some new ways that I might try to handle my stress at work?

What did I not understand today?

Choose one incident that happened this week that shows that I am better able to manage my reactions to stressful situations at work. Describe this incident on the back of this page and bring it with you for the next session.

MODULE IV:
WORKING WITH FAMILIES

Time Required

- 180 minutes
- 20 minute break included

Facilitator Preparation - General

✓ Recognizing Family Emotions – two options are possible
  - Option One: Family visitors are invited to attend the training session and talk about their experience of having a loved one with Alzheimer's Disease living in a long-term care facility.
  - Option Two: Show video excerpts of *Losing It All: The Reality of Alzheimer's Disease* or another excerpt of your choice. If an alternative videotape is preferred, make arrangements to obtain it 4-6 weeks in advance.
  - For either option **Handout 4.2: Recognizing Family Emotions** to have learners record their reactions.

✓ Caring Practice with Families
  - Option One: Rollercoaster, a board game, which involves responding to typical situations which arise with families. Use **Handout 4.3: Rollercoaster Game** and prepared situation cards.
  - Option Two: The Risk, a case study, which involves responding to a family situation for which there is no simple resolution. Use **Handout 4.4: The Risk – A Case Study.**

✓ Flip chart, paper, masking tape and dry erase or water soluble markers

✓ Sufficient photocopies of Module IV Handouts 4.1 - 4.5

- ✓ Videotape player and quiet music cassette
- ✓ Overhead Projector and Module IV Overheads 4.1 - 4.2
- ✓ Extra writing materials (pens and paper)
- ✓ Small game tokens to be moved around a board, dice
- ✓ Optional: One 'squish' ball (soft 2 inch pliable balls) for each table of participants to relieve stress throughout session
- ✓ Optional: Bag of Hard Candies used as condiments (to be evenly distributed amongst learners' tables)

Welcome Back! **5 minutes**

Preparation:

None

Method:

- Welcome back the participants and express pleasure that they have returned for this session.
- Tell them that they will have a chance to:
  - ✓ practice what they have learned about Alzheimer's Disease,
  - ✓ communicate what they have learned from the last three sessions,
  - ✓ relax and enjoy learning about the emotions that affect the actions of family members when visiting or discussing their loved ones, and
  - ✓ learn how to partner with families to improve the quality of life for residents.
- Tell them that, if they want to, they will have the opportunity to share their reflections from the last session with the group.

Icebreaker: What Do I Do? **10 minutes**

Preparation:

- Small cards with individual roles printed on them:
    a. Director of Nursing
    b. Pastor/Priest
    c. Caregiver
    d. Administrator
    e. Spouse
    f. Charge Nurse
    g. Long Distance Family Member
    h. Doctor
    i. Activity Professional
    j. Person with Alzheimer's Disease

Facilitator Notes:

This is a game of charades that portrays the characters with whom caregivers interact on a daily basis. It will be very interesting to see how the various roles are played out. More roles can be added by having more than one person with Alzheimer's Disease. The behaviours and emotions that will be portrayed in this icebreaker are those that will be examined in greater detail later in this module.

Method:

- Shuffle the cards and give one to each participant.
- Tell them not to show their card to anyone.
- Tell them that they will act out the role of the character portrayed on their card and the other members will guess who they are.
- The person who is 'acting' may not speak, but may use actions, behaviours, and emotions to portray their character.
- Tell them that each card has a letter in front of their character. This letter determines the order in which they will act out their role.
- Give them one minute to prepare.
- Start alphabetically with '*a*' and allow all participants to act.

- Those who do not wish to act can be replaced by the facilitator.
- Give each participant one minute to portray their character. If the participants have not guessed, the participant reveals their character.

Agenda 2 minutes

Preparation:

- Prepare a flip chart page ahead of time showing the **Agenda (Flip chart 4.1: Agenda)**.
- Post the agenda in a prominent place in the room using masking tape and leave it up for the duration of the session.

Method:

- Go over the agenda, mentioning that most of the time will be spent on:
  - ✓ Discovering strategies to work with family members
  - ✓ Understanding the fears and frustrations of family members
  - ✓ Realizing that caregivers' relationships with family members can affect residents
- Add that the group may not complete all items on the agenda.
- Tell the learners that the group will take time to discuss the important issues.

Flip chart 4.1: Agenda

Welcome Back	5 minutes
Icebreaker – What Do I Do	10 minutes
Agenda	2 minutes
Discussion Topics	3 minutes
Reflection Review	15 minutes
Mini-Lecture	10 minutes
Recognizing Family Emotions	45 minutes
Option One: Family Visitors	
Option Two: Video excerpt	
- BREAK -	20 minutes
Caregiving Practice with Families	35 minutes
Option One: Rollercoaster --A Board Game	
Option Two: "The Risk" --A Case Study	
Reflections	8 minutes
Evaluation	10 minutes
Wrap-up Discussion	25 minutes

Discussion Topics **3 minutes**

Preparation:

- Set up the overhead projector and screen ahead of time
- Show **Overhead 4.1: Discussion Topics,** or prepare a flip chart ahead of time showing the goals of the module.

Method:

- Put up **Overhead 4.1: Discussion Topics for Module IV**
- State that during this session we will talk about:
    - ✓ How families react to placing a family member with Alzheimer's Disease into a long term care facility
    - ✓ How caregivers can work with families to give the best quality care for the person who has Alzheimer's disease.

Overhead 4.1: Discussion Topics of Module IV

Working With Families

✓ **How families react to placing a family member with Alzheimer's Disease into a long term care facility.**

✓ **How caregivers can work with families to give the best quality care for the person who has Alzheimer's Disease**

Reflections Review

15 minutes

Preparation:

- Extra copies of **'Reflections Handout 3.2'** from last session.

Facilitator Notes:

Emphasize that sharing notes or thoughts from their **Reflections**, although very beneficial for all, are personal choices.

Use the time judiciously. Try to incorporate the reflections of as many participants as possible. If the participants have trouble sharing, do not belabour the issue. Move on to the new material. On the other hand, if discussions have overrun the time allotted, try and draw conclusions before moving on to the new material.

Method:

- Ask participants to take out their **Reflections** from last week.
- State that you are going to ask them to share their thoughts from their reflections. Tell them that there are no wrong answers and that they are free to talk about their own experiences or to add to others' experiences.
- Tell them that they can share if they want to, but they do not have to.
- Ask them to talk about the incident they wrote about in their reflection.
- Give participants time to answer and be encouraging to everyone.

Mini-Lecture: Working with Families **10 minutes**

Preparation

- Set up the overhead projector and screen ahead of time
- **Overhead 4.2: Working with Families**
- Facilitator review of mini-lecture notes: **The Role of the Family in Alzheimer's Care**
- Sufficient copies of **Handout 4.1: Working with Families**

Facilitator Notes:

This mini-lecture will serve two purposes. It will emphasize the roles that family members have played in the care of their loved ones and will serve as an introduction to the family visit that will occur just after this mini-lecture. The bolded text indicates words or sentences that **must** be said.

Method:

- Use the facilitator notes, **The Role of the Family in Alzheimer's Care,** to develop your mini-lecture. Do not read the notes – use them to develop your talk for the learners.
- Put up **Overhead 4.2: Working with Families** Present the facts simply. Do not use complicated words or sentence structure. Refer to the overhead as you speak. It is your prompt for the progression of the mini-lecture.
- Pass out **Handout 4.1: Working with Families**
- Ask the participants to fill in the blanks on **Handout 4.1: Working with Families** while you are speaking

Overhead 4.2:
Working With Families

- **The Caregiver and the Family**
- **Emotions:______.________._______.______**
- **Role change upon placement**
- **Family conflict:**

1.____________________

2.____________________

3.____________________

Handout 4.1: Working With Families

- The Caregiver and the Family
- Emotions

  ____

  ____

  ____

  ____

- Role change upon placement
- Family conflict:

  1.____________________
  2.____________________
  3.____________________

Facilitator Mini-Lecture Notes:
The Role of the Family in Alzheimer's Care

The Caregiver

Alzheimer's Disease not only affects the person with the disease, but their entire family. Those who work in the Alzheimer's field call **family caregivers 'the second patient.'** This is because the care that they provide to their loved one **is unending, consuming, stressful, exhaustive**, and often leads to a quick decline in their own health. Alzheimer's Disease also **affects the strengths and weaknesses of existing family relationships**. Throughout the course of the disease, families are forced to cope with an unending range of conflicting and difficult emotions.

Caregivers cope with feelings of **anger** as the disease their loved one is experiencing places increasing demands upon them. Often those with Alzheimer's Disease can appear deceptively well, yet still make difficult and unrealistic demands upon the caregivers. These unreasonable demands often cause anger and **guilt**. Feelings of guilt are compounded by feelings of being **overburdened** with care concerns. More guilt may be added if other **family and friendship roles must be neglected**.

Caregivers are often burdened with feelings of **embarrassment** because of the unusual behaviours of their loved one. They may feel that having a family member with a mental health disease means the family has been **disgraced**.

Caregivers suffer from **frustration** at being able to do so little, about having so **little control** over their own lives, and about the indecision that often accompanies the decisions they must make about the future. Others feel **abandoned** as friends and family members turn away. Many caregivers become **depressed, isolated**, and unsure about whom to turn to. Caregivers grieve for the loss of their normal way of living, and of the companionship of the person with the disease. This **grieving** is confused by the fact that the person is still alive in body but gradually slipping away in person. Adding to this confusion is the fact that on some days, their loved one behaves normally. Such days can cause caregivers to wonder if there is a problem, if it will go away, or if it is they themselves who are the problem.

Once the disease has progressed to the point where the caregiver can no longer care for their loved one at home, they experience tremendous guilt about placement in long term care. Their stress may increase if they feel guilty about having **'given up'** on their loved one and if they feel they have **failed** as a caregiver. Family members and friends may not understand that the caregivers home life has deteriorated, thereby adding to the caregiver's unhappiness.

Family caregivers whose loved ones reside in long term care do not stop being caregivers. Some caregivers **'double-up'** their caregiving role once the loved one has been institutionalized, in order to placate their own feelings of guilt. Many caregivers experience **difficulty in letting go** of their roles or their relationships.

The Family

Three types of conflicts generally exist within families who struggle with Alzheimer's Disease. First, some family members may disagree over the **severity of the disease** and the course of action to be taken. Second, they may disagree over the **roles of the main caregiver(s) and other family members**. Some family members disappear, others fulfill caregiving roles, while still others choose to help in less direct ways than hands-on caregiving. Third, other difficulties arise when the **main caregiver becomes overburdened and resentful** of the enormity of the task. Roles shift once again as the disease progresses, and placement in long term care becomes an option.

Recognizing Family Emotions

45 minutes

General Preparation:

- **Option One** – Family Members are invited to attend the group. More detailed instructions are given below
- **Option Two** – Excerpts from the videotape provided or a selection from the annotated videotape list provided below.
- Flip chart, paper and markers
- Sufficient copies of **Handout 4.2: Recognizing Family Emotions**

Facilitator Notes:

Caregivers report that interacting with a resident's family is often the hardest part of their job. When residents enter a facility they bring families with them that have highly developed ways of interacting that are often difficult to understand or change. Caregivers need to understand some of the typical emotions that families exhibit in order to optimize care for the resident and to rationalize behaviours that may be misdirected toward caregivers.

These activities will require careful attention on the part of the facilitator. If Option One is chosen, family members should be chosen carefully, paying attention to both the emotional state of the family members and the needs of the learners. If Option Two is chosen, the video excerpts may provoke a powerful response from the learners. Extra time may be needed for debriefing and discussion.

In either option, learners are asked to identify emotions that are expressed by family members. Since it can be very difficult to determine which emotion is expressed, the learners are asked to provide evidence that justifies their choice. Participants are encouraged to listen for the tone of voice, the choice of words and facial expressions of family members.

Since emotions are powerful motivators to change, participants are asked to suggest changes that caregivers could make that would improve the families' situations. This activity also asks participants to reflect on their own perspectives on working with families and to consider whether a change has occurred as a result of this learning experience.

The aim of these activities is to give caregivers an insight into the world of the family which is coping with Alzheimer's Disease. Insights will foster understanding, empathy, and tolerance of the family/caregiver interaction.

These activities may intrude on the break. Either the break time or the game period may be cut short to amend the time limit.

Option One: Family Visitors

Preparation:

- Invite one or two representatives of families which have a loved one who lives in long term care to visit your group. Let the family member know that they will be asked to talk about their feelings about having their loved one in long term care. Assure them of confidentiality and that their feelings will be respected. Tell them that you will be asking them some questions and that the caregivers may ask some questions also.
- The **Questions for Visiting Family** (printed below) is a letter with a list of questions that have been prepared for the family guests and should be delivered to them prior to the visit in order that they may adequately prepare their answers.
- The family members can chose to answer the questions or not, according to their wishes.
- Sufficient photocopies of **Handout 4.2: Recognizing Family Emotions**
- Prepare a thank you note for the family member(s)

Questions for Visiting Family

Thank you so much for agreeing to attend our *Pride in Alzheimer's Care* Course! The following is a list of possible questions that may be asked of you when you visit our training program. If you are uncomfortable about answering any of the following questions, please let me know at the following number (_ _ _-_ _ _ _) and I will ensure that the question(s) will not be asked.

1. Would you tell us about yourself?
2. Would you tell us about your loved one, the member of your family who has Alzheimer's Disease?
3. Would you tell us how Alzheimer's Disease has affected your family?
4. Would you tell us how your loved one came to be placed in long term care?
5. If you would not mind, would you tell us how you felt about placing your loved one in long term care?
6. Can you tell us what you like best about where your loved one now resides?
7. Is there some element of care that you wish you could change at he facility where your loved one resides?
8. What is one thing that you wish caregivers knew about your loved one?
9. If you could give one piece of advice to those who care for you loved one, what would it be?

Method:

- Pass out **Handout 4.2: Recognizing Family Emotions**
- Tell participants what they are going to listen to family members talk about trying to cope with loved ones who have Alzheimer's Disease. They may make notes but should concentrate their attention on the visitors.
- Invite your guests in and have them sit where they are most comfortable, either among the caregivers or facing them.
- Greet the family members and introduce them by name to your learners.
- Go around the room and have the learners introduce themselves to the family members.
- Tell the family members that you are going to ask them a few questions about their family member who has Alzheimer's Disease and their family's reactions to the situation. Assure them of confidentiality and of their prerogative to chose to not answer any question that they are not comfortable answering.
- Tell the families that the learners will be making some notes in order to organize their own thoughts and to learn from what is being said.
- The following questions are examples only. Add or delete questions as appropriate and to stay within the time available.
    - ➢ Begin by asking the family members if they would tell about themselves and about their family member who has Alzheimer's Disease.
    - ➢ Ask, "How did your family member come to be placed in long term care?" and "How did you feel about this?"
    - ➢ Ask, "How has Alzheimer's Disease affected your family?"
    - ➢ Ask, "What do you like best about where your loved one lives now?"
    - ➢ Ask, "What would be one thing that you wish you could change about how your loved one is cared for?"
    - ➢ Ask, "What is one thing that you wish caregivers knew about your family member?"

  - Ask, " What is one piece of advice you would like to give to those who care for your loved one?"
- Thank the family members for coming on behalf of yourself and the caregivers. Tell them that their input was very meaningful and has added a new dimension to care.
- Escort the family to the door and thank them again for coming.
- Tell the learners to take a few moments and think about what they have just heard from the family members.
- Ask them to work with a partner to fill out the handout. Give them five minutes.
- In the large group ask what was one emotion that they saw or understood to be expressed by the family member.
- Ask the participants why they thought that emotion was expressed.
- After each emotion and evidence, ask the participants if they thought there was anything that caregivers could do to improve the situation. Ask them if there was something that caregivers should not be doing.
- Record their answers on flip chart paper.
- Ask them to imagine themselves in that family's situation. Ask them if their perspective has changed and why (or why not)?
- Ask them to sign the thank you card that you have prepared for the family.

During the break time ask the participants to talk about their work experiences with family members who remain involved in the care of their loved one with Alzheimer's Disease.

- BREAK - **20 minutes**

Option Two: Videotape Excerpts

Preparation:

- The provided videotape excerpts must be carefully previewed before group viewing. The activity requires that each segment should be started and stopped before moving on to the next segment.
- If the provided videotape is not appropriate, a list of suggested videos have been included below. They will have to be pre-ordered at least 4-6 weeks before the scheduled session.

Alternative Videotape Resources

1. Filmakers Library. (1990). *You Must Remember This: Inside Alzheimer's Disease*. New York, NY: Author.
2. University of Pittsburgh Medical Center. (1990). *Families Caring*. Pittsburgh, PA: Alzheimer's Disease Research Center and the Division of Creative Services.
3. Elder, P. & Forsythe, J. (1992). *Giving Care, Taking Care*. Long Beach, CA: FHP Foundation.
4. Terra Nova Films. (1992). *Dealing with Alzheimer's Disease: Facing Difficult Decisions*. St. Paul, MN: Ramsey Foundation.
5. Catanzarit, G. (1993). *Memories of Love*. Pittsburgh, PA: Alzheimer's Disease Research Centre.

Method:

- Pass out **Handout 4.2: Recognizing Family Emotions**
- Tell the participants that they are going to watch short video clips
- about families who are trying to cope with loved ones who have Alzheimer's Disease.

- After each segment, stop the video-tape.
- Tell the learners to take a few moments and think about what they have just heard from the family members.
- Ask them to work with a partner to fill out the handout. Give them one minute to discuss and then restart the videotape. There are five segments. The fifth is optional.
- In the large group ask what was one emotion that they saw or understood to be expressed by one of the family member members.
- Ask the participants why they thought that emotion was expressed.
- After each emotion and evidence, ask the participants if they thought there was anything that they could do as caregivers to improve the situation for the family. Ask them if there was something that they should not be doing.
- Record their answers on flip chart paper.
- Ask them to imagine themselves in one of the families' situations. Ask them if their perspective on working with families has changed and why (or why not)?
- In a large group, discuss how they might feel about having a loved one with Alzheimer's Disease and having to place that loved one in a long term care facility.

During the break time ask the participants to talk about their work experiences with family members who remain involved in the care of their loved one with Alzheimer's Disease.

- BREAK - **20 minutes**

Handout 4.2: Recognizing Family Emotions

1. Emotion: ____

Evidence: ____

____

2. Emotion: ____

Evidence: ____

____

3. Emotion: ____

Evidence: ____

____

4. Emotion: ____

Evidence: ____

____

Word Bank:

excited
worried
distraught
confused
heartache
indignant
happy
frantic
angry
grief
troubled
offended
sad
free
calm
denial
scared
upset
anxious
guilty
afraid
stricken
relieved
provoked
overjoyed
burdened
resentful
anguish
agitated
indecisive
lonely
bitter
apprehensive
overwhelmed
distressed
resigned

Caregiving Practice with Families

General Preparation:

- **Option One** -- Learners participate in a board game that involves situations in which caregivers decide on appropriate interactions with families. More detailed instructions are given below.
- **Option Two** – Learners participate in a case study for which there is no simple resolution. More detailed instructions are given below.
- Sufficient photocopies of **Handout 4.4: "The Risk" – A Case Study** or **Handout 4.3: Rollercoaster Game.**

Facilitator Notes:

Alzheimer's Disease involves not just the person with the disease, but the whole family. When a loved one enters a long term care facility, the family often continues to play a large role in their loved one's care. Caregivers who work in the facility find that they are not just assigned a new resident, they are also assigned a new family.

Family members grow to rely on caregivers for the safety, happiness and well-being of their loved one with Alzheimer's Disease. It is a tremendous responsibility when caregivers are assigned to work with several residents on one shift. All families have a history of well-established roles and inter-interpersonal relationships. Caregivers can easily become involved in situations in which family dynamics, which have evolved over a number of years, must be handled with as much care as must be given to the person with the disease. Working with families to provide care for their loved ones requires thoughtful consideration, tact and diplomacy on the part of the caregiver.

The following two options explore the complicated arena of family relationships and caregiving, an arena where there are seldom simple answers.

Option One: Rollercoaster -- A Board Game for Caregivers Working With Families

35 minutes

Preparation:

- Small tokens to move around the 'board'
- Sufficient photocopies of Handout 4.3: Rollercoaster Game for each pair of participants.
- Question cards photocopied and cut, enough so there is a set for each pair of participants.

Facilitator Notes:

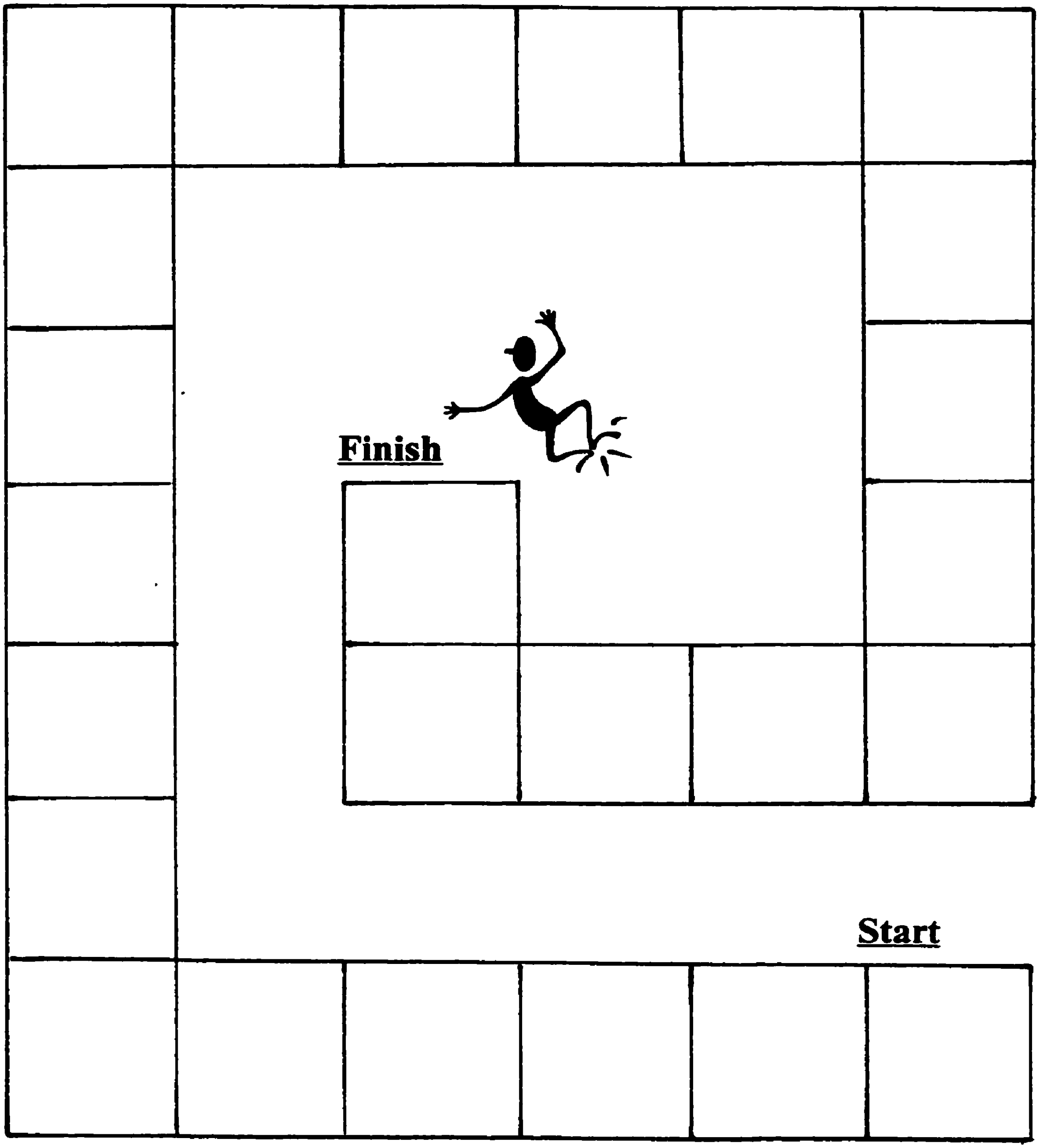
This game is used to explore a number of specific situations in which caregivers must interact with families. The cards raise questions for which there is more than one possible answer, but one response that may be more appropriate than others. The aim is to find the most appropriate response with the highest score value. The numbers on the bottoms of the cards indicate the answer's score. Better answers score higher and poorer responses score lower. This game can be modified so that more than two players can play at one time. The aim is to reach the 'Happy Resident' at the centre.

Method:

- Each person identifies their own game token and puts it at the `Start.'
- The cards are placed face down on the board.
- Play follows the board. The first player selects a card from the pile and reads the situation and possible responses to the player on the right. The player on the right selects a response, then moves the number of spaces indicated for that response.

- The player who has just answered selects a card and reads the situation and possible responses to the next player on the right.
- Play continues for 20 minutes or until a player reaches the Happy Resident. If a pair finishes their game early, they may join in the discussion with others who are still playing.
- When play has stopped, the learners are asked to stop and think quietly for one to two minutes about any situation that they had difficulty answering during the game.
- Going around the room, ask participants to talk about the scenarios that they had difficulty answering. Encourage others in the group to offer their input to clarify difficult situations for caregivers. Explain some of the possible responses are better than others.
- Ask the participants what they learned about working with families? Ask what they might try doing differently when they work with residents' families and why.

Handout 4.3: Rollercoaster Game



Questions for the board game follow:

Mrs. S's family has complained to the Director of Nurses that you wish Mrs. S Merry Christmas every time you go into the room during the holiday season. Mrs. S is Jewish. What do you do?

a. Stop speaking to Mrs S. when you go into the room.
b. Simply say happy holidays instead of Merry Christmas.
c. Talk to Mrs. S and her family and find out which holidays are important to the family and be in good spirit when it is appropriate for Mrs. S

a.0, b.1, c.3.

You notice that Mrs. C comes every day to see her husband. You also notice that she looks more worn out each time you see her. The visits with her husband are not easy as he is very angry with her at times. What do you do?

a. Tell Mrs. C to not come for a while
b. Reassure Mrs. C that Mr. C is very well taken care of at your facility and that he can manage well on his own.
c. Ask Mrs. C. what her hobbies are and suggest that she should spend some time looking after herself. Reassure her that her husband is well looked after.

a.1, b.2, c.3.

Mrs. T has been brought by her daughter for admission to your facility today. Mrs. T has been settled into an activity after being shown around and it is time for her daughter to leave. The daughter looks completely devastated. What do you do?

a. Get her out the door as fast as possible
b. Reassure her that she has done the best thing for her mother and that her mother will be well looked after.
c. Ask the daughter is she would like to sit down and observe her mother for awhile before she leaves.

a.0, b.3, c.2

You have been having a difficult time getting Mr. B to shave first thing in the morning. What do you do?

a. Shave him yourself whether he wants to or not.
b. Ask his family if there was a particular time or way that Mr. B like to shave.
c. Ask the charge nurse what to do.

a.0, b.3, c.1

Mrs. S's daughter is always giving you advice, whether you want it or not, about how to care for her mother. What do you do?

a. Tell the nurse in charge that you are sick of the daughter's advice and that you want to be left alone.
b. Politely agree with everything Mrs. S's daughter says and then do as you have always done for her mother.
c. Listen to what she says, she may say something that will make your work with her mother much easier.

a.0, b.0, c.3

Mrs V is upset because every time she comes to visit her sister, she is incontinent and wet. She comes looking for you. What do you do?

a. Promise to toilet her every hour even though you know that is not a possibility.
b. Explain the toileting procedure to Mrs V and then quietly change her sister and bring her back.
c. Tell Mrs V that her sister is not your patient.

a.0, b.3, c.0

The children of Mr. W are trying to fix up his room. They have brought in some furniture that has been part of his bedroom furniture for most of his life. It is not easy for you to work around it when you care for Mr. W. What do you do?

a. Complain to the nurse in charge that the room is impossible to work in.
b. Compliment the family for trying to make their dad feel at home with his own furniture.
c. Compliment the family on their efforts and ask if there is a way to arrange the furniture to make it easier for their Dad to move around.

a.0, b.2, c3.

Mr. X has a large extended family that comes to visit in large groups. Mr. X becomes very confused with multiple conversations and a number of people moving about. What should you do?

a. Suggest to the family, that some might like to take a walk throughout the building while just one or two visit with Mr. X at one time.
b. Tell the family that they are only confusing their Dad by coming in big bunches.
c. Ask to speak to one of the eldest children and mention that you have noticed that their Dad becomes pretty upset when there are large numbers of visitors at one time, but really enjoys their company one at a time.

a.2, b.0, c.3

When Mrs. T visits her husband, she talks in front of him, about him as if he wasn't there. What do you do?

a. Tell her that you do not like talking about her husband as if he wasn't there.
b. When you answer her, you make a concentrated effort to include her husband in the conversation.
c. Talk to Mr. T about Mrs. T as if she wasn't there.

a.1, b.3, c.0

Mr. L complains to you that his wife has been getting worse this past year and he can not understand why. What do you do?

a. Explain to him that Alzheimer's Disease is like that; this kind of progression is expected.
b. Become defensive and tell him that you are doing the best you can.
c. Courteously disagree and tell him that she is doing as well as can be expected.

a.3, b.0, c.0

When Mr. C's wife is leaving the facility, he becomes very upset and tearful. This, in turn, upsets his wife. What do you do?

a. Watch carefully and just before she leaves, distract Mr. C. by asking him to help you take some books, towels, laundry, etc. down the hall.
b. Tell Mr. C that he shouldn't make such a fuss because it only upsets his wife.
c. Tell Mrs. C it is ok to just leave because her husband settles down on his own after a while.

a.3, b.0, c.1

Mrs. S becomes really upset that her favourite dress is not in her closet when her family arrive to visit. The family is upset by the severity of her reaction. What do you do?

a. Remain calm and suggest that she and you go and look for it.
b. Try and reassure everyone at the same time.
c. Redirect her attention and ask for her advice on which of her children is the tallest, prettiest, oldest etc.

a.2,b.0,c.3.

Mr. V has hit you in the eye after he became upset when he lost his teeth. His son is mortified. What should you do?

a. Remain calm, give yourself a short time out and reassure the son that you are not angry and that you understand that these behaviours are sometimes part of the disease.
b. Go and get ice for your eye and get someone else to care for him for the rest of the shift.
c. Tell the son to get a lawyer.

a.3, b.1, c.0

When Mrs. V's family comes to visit with Mrs. V, they do not seem to know what to do. Usually they sit all in a row and say nothing and no one looks very happy. What should you do?

a. Suggest that Mrs. V show the family some pictures that were taken of her at the last Strawberry Social.
b. Suggest to the family that the next time they come, they could bring some old picture from Mrs V's past.
c. Suggest to the family that they bring in a family-favourite game, or video of a family outing.

a.3, b.3, c.3

By the time Mr. T's son gets off work and comes to visit his Dad, it is often sundowning time for his Dad. The son is very upset that his Dad will not sit and visit with him. What do you do?

a. Tell Mr. T to go and sit down with his son and visit him.
b. Tell Mr. T's son that this is a part of the disease and perhaps the visit would go better if he walked with his Dad.
c. Tell Mr. T's son to come back another time.

a.0, b.3, c.0

Mr. P has found a friend in Mrs. G at your facility. The often hold hands and occasionally kiss. Mrs. P arrives to see Mrs. G embracing her husband. She becomes upset. What do you do?

a. Assure Mrs. P that this sometimes happens with Alzheimer's Disease and that Mr. P thinks that Mrs. G is Mrs. P.
b. Distract Mr. P and tell him that someone wonderful has come to see him. Take him to a private area where you have already brought Mrs. P.
c. Take Mrs. P by the arm and go up to Mr. P and tell him that his wife is here to see him.

a.2, b.3, c.0

Mrs. B keeps telling her son that she sees children playing outside her window. Her son cannot see any children and becomes upset with her insistence. What do you do?

a. Tell her son that there are no children playing in the area.
b. Mention to her son, that hallucinations are sometimes part of Alzheimer's Disease and the hallucinations appear absolutely real to her Mom.
c. Explain that sometimes it is better not to argue and better still to placate and distract rather than to dwell on the hallucination.

a.0, b.3, c.3

Mr. T's glasses are broken and he says that you broke them. The family members are upset and want you to pay for something you did not do. What do you do?

a. Confront Mr. T and tell him that you did not do it.
b. Talk with the family and explain that you did not do it. Also explain that suspiciousness is part of the disease.
c. Report the incident to your superior.

a.0, b.3, c.3

Mrs. J's family visit during the most difficult part of Mrs. J's day. They keep her busy and happy despite her desire to pace and fidget. The family leaves quietly after visiting for an hour. What do you do?

a. Thank them for coming and helping her with the hardest part of her day.
b. Say nothing to them.
c. Tell them how much you appreciate what they do for her.

a.3, b.0, c.3

It is holiday time and Mrs. B family, who although they live close by, do not visit. She is very lonely and cries because she misses her family so much. Her family calls and asks you how she is. What do you do?

a. Tell them how lonely their mother is and ask why they don't visit.
b. Tell them that they make things more difficult for their mother by not visiting.
c. Honestly tell them how their mother is. Do not be judgmental.

a.0, b.0, c.3

Mr. P calls several times each week, in addition to visiting his wife. Each time, he asks how she is, what she is doing and if he can do anything more. What should you do?

a. Reassure him that his wife is fine and that you will take good care of her.
b. Ask him why he calls so much.
c. Explain that there is no need to call, as his wife is fine.

a.3, b.0, c.0

When Mrs. B's daughter visits, she brings up old family issues that often end up upsetting Mrs. B. What should you do?

a. Explain to Mrs. B's daughter that her mother may not be able to comprehend the reasoning behind the issues; she only recognizes the anger and pain.
b. Encourage Mrs. B's daughter to talk about other topics that are pleasurable for them both.
c. Suggest that her mother would enjoy a hand massage or having her hair brushed. Supply the lotion and brush.

a.3, b.3, c.3

When the daughter who lives a thousand miles away calls, she asks several times how her mother is. How do you respond?

a. Tell her that her mother is fine and keep repeating it.
b. Tell the daughter honestly, both good and bad what has been happening to her mother.
c. Reassure her that her mother is being well taken care of. Emphasize the positive, but do not lie to her.

a.0, b.2, c.3

Mrs. B is always rummaging through other resident's belongings. Other residents and their families are upset. What do you do?

a. Make a rummaging drawer for Mrs. B. Ask her family to bring in old things of hers and put them in the top drawer of her dresser.
b. Ask the family to bring in things and make a rummage drawer with her. Tell her the drawer is filled with things that she might need.
c. Every time she goes into another resident's room, go and get her and tell her that she should not be there.

a.3, b.3, c.1

You know that a care conference is coming up for Mrs. S. What do you do for her family?

a. Nothing.
b. Call her family and encourage them to come for the conference.
c. Send them a routine form letter advising them of the date.

a.0, b.3, c.1

When Mr. P's son and daughter came to visit, they sat and talked earnestly with Mr. P for quite a while. He seemed fine at the time but by the next day, he was terribly upset and inconsolable. What should you do?

a. Call the son and daughter and ask them if there was something that was discussed that could have upset their father.
b. Keep trying to get from Mr. P what is wrong.
c. Ask the family to come back in and talk with Mr. P.

a.3, b.0, c.0

Mrs. D's brother comes to visit her first thing in the morning. When he arrives she is not dressed, nor is her hair combed. He is very upset and tells you that you are not doing your job. What do you do?

a. Explain that his sister is hard to get along with in the morning and that you cannot do a thing with her without getting into a fight.
b. Explain that Mrs. D likes to get dressed and fixed up after her mid-morning snack and you like to work with her preferred schedule, not yours.
c. You get her dressed and comb her hair on the spot despite her loud verbal protests.

a.0, b.3, c.0

Option Two: 'The Risk'-- A Case Study 35 minutes

Preparation:

- Sufficient copies of **Handout 4.4: "The Risk" – A Case Study** .

Facilitator Notes:

The aim of this activity is for participants to become aware of the role of family members of those they care for and how those roles can impact care. The questions are meant to create discussion about what occurred in the case, what role caregivers played, and what role they should or should not have played. The questions also ask the participants to put themselves into the situation and reflect what they might have done if they were the caregivers in question.

It is important for facilitators to understand that their role in this activity is to guide the participants' exploration of the questions. It is inappropriate for facilitators to assign guilt, or to assume there is a correct answer. This case study explores the conundrums that many caregivers face in the delivery of care. It serves to illustrate that often care concerns have no easy answers.

Method:

- Pass out the case study and questions to the participants.
- Ask for a participant to read the case study or read it out loud yourself.
- Ask participants to find a partner. When they have found a partner, ask them to read the questions together and discuss them.
- Give the learners 5 minutes to discuss their answers.

- Open the discussion to the floor and lead the discussion of the questions, ensuring that as many participants as possible have the opportunity to speak.
- Give the group 10 minutes to explore their answers. Thank them for their answers.

Handout 4.4: Case Study

Maurice Cameron, 75 years old, was admitted to the local Nursing Home one year ago. He was an amiable, pleasant man diagnosed with Alzheimer's Disease. At the time of admission, he received only the drug Arisept for the disease, which he had been accepting very well. He had lived in the local area and his wife and one of his two daughters lived nearby.

His wife, Eva, visited faithfully every day and stayed several hours.

She was a sweet old lady who had nothing but kind things to say to the staff. At times, Maurice was verbally abusive to his wife. If she did not arrive at the appointed hour each day, he would become agitated and bother the staff with constant demands, asking where his wife was, and why wouldn't they let him phone her. When they gave in and phoned his wife so that he could talk to her, he would become very abusive to his wife. Some of these calls were intercepted by the staff and they found his wife crying on the telephone.

After several months, the staff noticed that Maurice seemed considerably worse. He made less sense when he talked, started crying more often, and would become much more agitated and aggressive during the night. The staff tried medicating him at night. However, this had no effect on him during the night and he became more confused during the day. One cold winter night, he was found at the entrance to the home trying to get back in. He had obviously escaped through a coded door and had found his way back to the entrance. No one had noticed his absence. When asked why he had left, he replied that he had wanted to check his bird feeder outside his window. After that incident, he was labeled an 'escape risk' and was constantly watched by the staff.

The staff noticed that his wife, Eva, started to deteriorate as well. When she visited, she did not look well, and during one visit, she collapsed. An ambulance was called and she was taken to the hospital. The second day after this incident, Eva arrived back at the nursing home to resume visiting her husband on a daily basis. Each time she visited, she would ask the staff how her husband had been. The staff would truthfully tell her what events had taken place since her last visit. She seemed to take the news well each time when it was given, although after several weeks she began to look terrible, started losing weight, and often cried as she was leaving the facility.

Maurice's children visited irregularly. His elder daughter was surly and complained often to the staff about the poor quality of care that her father was receiving. The other daughter lived so far away that she phoned more than she visited. When she called, she often asked how her father was. The staff reported for a long time that all was well. More recently, when Maurice had become an escape risk and a problem for the staff, they were less forthcoming. Finally, the administration and staff wanted him removed from the facility to a locked unit at another facility. The family did not want him moved and did not want him given night medication.

Questions for discussion:

What role does each member of Maurice's family play?

What did the staff do well in this case?

What errors did the staff make with Maurice's care, if any?

What could the staff have done differently?

What would you have done if Maurice were part of your work assignment during the day? During the night?

How does this case change (or not change) the way that you work with residents' families and why.

Pride in Alzheimer's Care Evaluation 10 minutes

Preparation:

- Have sufficient copies of **Handout 4.5: Pride in Alzheimer Care Evaluation** for each participant.

Facilitator Notes:

This evaluation begins the process of closure to the program. It is made up of two components: a reaction questionnaire and a spoken narrative response.

Tell the participants that the program is coming to a close and that you would like them to think carefully for a few moments about the entire program before they respond to the questionnaire. Briefly review the modules, mentioning the topic of each one, and particular highlights that come to mind. Urge them to take their time responding to each question.

Method:

- Pass out copies of the evaluation.
- Ask participants to complete their evaluation of the course individually.

Handout 4.5: Pride in Alzheimer's Care Evaluation

1. During this program, I learned the fundamental components of giving care to those with Alzheimer's Disease.

Strongly Agree Agree Disagree Strongly Disagree

2. During this program, I learned how to communicate better with those whom I care for who have Alzheimer's Disease.

Strongly Agree Agree Disagree Strongly Disagree

3. During this program, I learned about Alzheimer's Disease and how it affects those with the disease.

Strongly Agree Agree Disagree Strongly Disagree

4. During this program, I learned about several methods to reduce stress.

Strongly Agree Agree Disagree Strongly Disagree

5. During this program, I learned about the impact of Alzheimer's Disease on families.

Strongly Agree Agree Disagree Strongly Disagree

6. I found the content material in this program excellent.

Strongly Agree Agree Disagree Strongly Disagree

7. The information that I learned in this program will be useful to me at work.

Strongly Agree Agree Disagree Strongly Disagree

8. The learning activities used in this program added to my understanding of the content materials.

Strongly Agree Agree Disagree Strongly Disagree

9. The facilitator was able to explain the material clearly.

Strongly Agree Agree Disagree Strongly Disagree

10. The facilitator used teaching strategies that helped me to learn.

Strongly Agree Agree Disagree Strongly Disagree

11. This program has changed the way that I give care to those with Alzheimer's Disease.

Strongly Agree Agree Disagree Strongly Disagree

12. I would recommend this program to other caregivers.

Strongly Agree Agree Disagree Strongly Disagree

Wrap-up Discussion

25 minutes

Preparation:

- None

Facilitator Notes:

This activity is meant to help participants think about the whole program; about what aspects have been most meaningful to them and what aspects could be improved; and to bring closure to the time spent together.

Method:

- Find a seat that places you amongst the participants or closes a U-shaped seating arrangement.
- Inform the participants that this activity ends to your time together and that you are looking forward to sharing their final thoughts.
- Tell them that you would like them to take a few moments and reflect on all four sessions. Tell them that you would like to know just two things. Ask them to think about the first question: If you could change anything about the program in general, what would it be?
- When they have had a few moments to reflect, tell them that you will go around the room and give everyone an opportunity to speak.
- After everyone who wishes to has spoken, ask them to think about the second question: How will you deliver care to residents that is different now than before you had this program?
- After giving the participants a chance to reflect, ask each in turn for their comments.
- Ask if anyone has anything more they would like to say.
- Thank them very much for coming.