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## Alzheimer's Toolbox: A Caregiver's Guide

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Alzheimer's Toolbox: A Caregiver's Guide

by

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Submitted to the Occupational Therapy Department

of the

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in partial fulfillment of the requirements

for the degree of

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## Approval Page

This Scholarly Project Paper, submitted by Kristen Eastwood, MOTS and Gerry Smith, MOTS in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Faculty Advisor

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Date

## PERMISSION

Title Alzheimer's Toolbox: A Caregiver's Guide

Department Occupational Therapy

Degree Master's of Occupational Therapy

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## DEDICATION

The authors acknowledge the family members with Alzheimer's disease who have inspired the creation of this scholarly project. We would like to give tribute to those loved ones who have been so brave during their illness. The love and care they have imparted to us in the past has helped to make us who we are today.

## ABSTRACT

“Alzheimer’s disease is the most common cause of dementia in North America and Europe” and “accounts for sixty percent of all irreversible dementia cases” (Moore, 2003, p. 50,126). Along with the 4.5 million Americans who suffer from Alzheimer’s, there are also the caregivers who are suffering alongside their loved one. The stress of caring for a loved one with Alzheimer’s can be overwhelming. This affects the quality of life for those with Alzheimer’s and the health of the caregiver.

A comprehensive literature review was conducted to explore and identify effective techniques and interventions, pertinent to both the caregiver and patient's quality of life. The literature review was conducted using several sources: Harley French Library, Alzheimer’s Association National website, Alzheimer’s Association of the Great Plains website, Casper College Library, and brochures from local long-term care facilities. The literature determined that although there is a considerable amount of information available regarding Alzheimer’s disease, the information is not easily accessible, nor organized in an easy to use, consumer friendly format.

The findings from the literature resulted in the development of the *Alzheimer’s Toolbox: A Caregiver’s Guide*. *Alzheimer’s Toolbox: A Caregiver’s Guide* is an easy to use and understand booklet of information. Toolbox is included in the title so the readers understand that it contains the tools needed to help improve the quality of life for all involved.



*Alzheimer's Toolbox: A Caregiver's Guide* utilizes occupational therapy techniques designed to help reduce stress and improve the quality of life for both caregivers and the persons with this disease. It includes resources for when the caregiver needs additional support or wants to enhance their own performance. The Toolbox addresses the changes in the duties the caregiver assumes due to decreased functioning of the person with AD. Activities of daily living, financial responsibilities, home management and legal decisions are some of the areas where changes are addressed.

It is the authors hope to improve the quality of life for those who are living with AD and their caregivers by providing a toolbox of interventions, environment alterations and coping strategies. The proper use of the Toolbox will allow the users to modify the specific areas or tasks most appropriate for the individual's particular situation and provide the caregiver guidance as to when additional services might be needed.

## CHAPTER I

### INTRODUCTION

“Alzheimer’s disease is the most common cause of dementia in North America and Europe” and “accounts for sixty percent of all irreversible dementia cases” (Moore, 2003, p. 50,126). Along with the 4.5 million Americans who suffer from Alzheimer’s, there are also the caregivers who are suffering alongside their loved one. They are suffering the slow loss of a spouse, parent, and/or companion as well as the loss of their life, as they planned it, with this individual. According to Rodriquez et al. (2003, p. 329) “from the emotional point of view, caregivers claim loss of free time, friendships, and hobbies, and feel isolated in the social context: sometimes the patient’s death is thought of as a solution.”

A comprehensive literature review was conducted to explore and identify effective occupational therapy techniques and interventions to help improve the quality of life for both the caregiver and the person who is diagnosed with Alzheimer’s. The findings from the literature resulted in the development of the *Alzheimer’s Toolbox: A Caregiver’s Guide*.

The *Alzheimer’s Toolbox: A Caregiver’s Guide* is based on research and evidence based practice, in order to provide information that, when used appropriately, minimizes

stress or provides solutions for caregivers. This in turn will increase the quality of life for those with Alzheimer's. The sections include:

1. Introduction
2. Definitions of Alzheimer's disease
3. Important terms
4. Role of occupational therapy
5. Caregiver challenges and interventions
6. Home activities
7. Community resources
8. Future placement options

These interventions and resources were identified in the reviewed literature as effective methods to reduce stress and increase the quality of life for those with Alzheimer's and their caregivers. The interventions focus on: 1) coping and stress management; 2) easy home modifications; 3) maintaining overall health; 4) communication techniques; 5) home activities and; 6) dealing with loneliness or depression. The toolbox is designed for use by caregivers in the home, private or professional, or day care settings.

An occupational therapy model or frame of reference provides a specific focus and direction for interventions. The occupational therapy model used in the design of the toolbox is the Ecology of Human Performance (EHP) Model. The main constructs of the model include person, context, task and performance. Occupational therapy uses the EHP model to alter environments and tasks to fit the individual's functional abilities within his/her context (Dunn, Brown, & Youngstrom, 2003). The product incorporates interventions focusing on changing the person, task or environmental variables to

improve the quality of life for the person with Alzheimer's Disease (AD), and ease some of the challenges of the caregiver.

The authors' personally experienced the lack of information/support provided to the private caregiver and believe the toolbox's contents could change lives for the better. Using occupational therapy's holistic treatment approach with caregivers in need and not receiving services from other sources, the toolbox could be of invaluable benefit on many levels.

The chapters of this scholarly project will be presented in the following order:

- Chapter II – A review of literature presenting information on Alzheimer's disease (AD), primary caregivers, roles and challenges of caregivers, impact on caregiver, options for long term care, and role of occupational therapy. This chapter includes a description of the *Alzheimer's Toolbox: A Caregiver's Guide*, including the occupational therapy framework model used.
- Chapter III – An explanation of the methodology used to gather information for the development of the *Alzheimer's Toolbox: A Caregiver's Guide*.
- Chapter IV – *Alzheimer's Toolbox: A Caregiver's Guide* including definitions of AD, important terms, role of occupational therapy, caregiver challenges and interventions, home activities, community resources, and information regarding future placement options.
- Chapter V – A summary of the information gained and presented in the *Alzheimer's Toolbox: A Caregiver's Guide*.
- References

## CHAPTER II

### INTRODUCTION

Dementia is the significant loss of intellectual abilities severe enough to interfere with social and occupational functioning. It is a progressive disease that becomes worse over time, due to the continued loss of brain tissue resulting in memory loss and can eventually be fatal (Moore, 2003). There are two common types of dementia; Alzheimer's type dementia and non-Alzheimer's type dementia. This literature review and scholarly project will focus specifically on Alzheimer's type dementia.

"Alzheimer's disease is the most common cause of dementia in North America and Europe" and "accounts for sixty percent of all irreversible dementia cases" (Moore, 2003, p. 50,126). According to the National Institute on Aging (2006, ¶4)

Scientists think that up to 4.5 million Americans suffer from AD. The disease usually begins after age 60, and risk goes up with age. While younger people also may get AD, it is much less common. About 5 percent of men and women ages 65 to 74 have AD, and nearly half of those age 85 and older may have the disease.

Along with the 4.5 million Americans who suffer from Alzheimer's, there are also the caregivers who are suffering alongside their loved one. They are suffering the slow loss of a spouse, parent, and/or companion as well as the loss of their life, as they planned it, with this individual. According to Rodriguez et al. (2003, p. 329) "from the emotional point of view, caregivers claim loss of free time, friendships, and hobbies, and feel isolated in the social context: sometimes the patient's death is thought of as a solution."

The focus of the literature review and subsequent scholarly project is on the identification and development of options, ideas and suggestions for the caregiver, essentially a caregiver's toolbox. The review also identified effective occupational therapy techniques and interventions that are pertinent to the caregiver to improve their quality of life, as well as the quality of life for individual with AD. One primary reason for this focus is that both of the students involved in this project have close relatives who have been diagnosed with Alzheimer's disease (AD). They have helped with or been responsible for the care of their family member.

### ALZHEIMER'S DISEASE

Alois Alzheimer first identified Alzheimer's disease as a condition in 1907. It is a progressive terminal type of dementia of unknown cause involving progressive deterioration of the brain and is associated with the neuritic plaques and neurofibrillary tangles in the brain (Porth, 2002). Alzheimer's causes a loss of memory function starting with the short-term memory which continues until it also eventually destroys long-term memory and motor control.

"Mild cognitive impairment (MCI) is a term used to describe changes in cognition that are greater than those typically seen in the aging process and often represent a transitional period between normal aging (NA) and Alzheimer's disease (AD)" (Greenaway et al. 2006, p. 79). According to Forstl and Kurz (1999), as AD progresses the individual commonly experiences three to four stages which are presented as follows:

### **Pre dementia Stage**

In the pre dementia stage, individuals will use memory aids to mask cognitive decline. They may avoid complicated situations or decisions and tend to hide memory loss, when it occurs. “Memory loss is the core symptom of AD and appears from an early stage in most patients...” (Kashiwa et al. 2005, p. 700). Family and friends may notice social withdrawal or depressive symptoms up to five years before a clinical diagnosis is made. The severity of memory decline denies individuals the ability to perform activities of daily living as the stages progress (Sevush and Leve, 1993).

### **Mild Dementia**

Mild dementia is the second stage in the progression. Clinical diagnosis is usually prompted by the increased symptoms that occur during this time. At this stage, individuals may have periods of time with decreased AD symptoms, in which their memory may be clear. According to Forstl and Kurz (1999, p. 288), “A significant impairment of learning and memory is the outstanding clinical feature.” Language difficulties, known as aphasia and visual perceptual problems interfere with activities of daily life such as: driving, dressing, grooming, eating, and social interactions. It is not recommended that an individual drive once they have reached the second stage because of these rapid memory changes and visual inattention.

### **Moderate Dementia**

The third stage, moderate dementia, is characterized by the individual living in their past life. They often try to go home to a place where they grew up as a child and often misidentify family, friends, and strangers. In this stage, they also lose their ability to read, write, plan, and organize. Once the disease has progressed to stage three, the

client requires moderate assistance and close supervision to function. Activities with longer sequences such as: using household appliances, dressing, and eating become too difficult for the individual to perform independently, and can pose a danger to individuals with AD. The risk for falls also significantly increases as their gait, posture and decision-making ability changes.

There are significant behavioral changes in this stage. According to Lauter and Perry (as cited in Forstl and Kurz, 1999, p. 289) “20% of patients develop hallucinations” in this stage. Devanand et al. (1997) indicate, “Aimless and restless activity like wandering, hoarding, etc., are common” (as cited in Forstl and Kurz, 1999, p. 289). “Behavior often becomes the way people with Alzheimer’s communicate their feelings and needs to others” (Petersen, 2002, p. 179). Many patients with AD suffer from anosognosia, which is the inability to recognize their illness and the effects it has on their everyday life. “Such patients ignore advice from caregivers and increase the burden on caregivers, while anosognosia also may cause accidents and worsen the prognosis of the patient” (Kashiwa et al. 2005, p. 697-698).

The loss of memory and/or communication skills robs the person with AD of contributing to their own plan of care. “Patients often misunderstand and misinterpret nursing interventions, and this may lead to aggressive reactions” (Forstl and Kurz, 1999, p. 289). Temper tantrums and lack of emotional control are likely to occur in this stage and are often coupled with physical and verbal aggression regardless of the individuals past personality traits.

The strain on the caregiver significantly increases at this point. They must care for a loved one who has become aggressive, disoriented, restless and incontinent. Due to the



increased strain on the family and the caregiver, this becomes the most common time for consideration and placement of the individual into a long-term care facility.

### **Severe Dementia Stage**

The final stage in the process is known as the severe dementia stage in which most cognitive functions such as language skills, memory and motor planning are impaired. Language skills diminish into short or single word phrases and eventually disappear. Long-term memory also weakens and eventually becomes inaccessible to the person with AD. Patients with AD have disrupted circadian rhythms resulting in sun downing, or confusion of day and night. They require maximum assistance to perform activities of daily living (ADL) such as bathing, toileting, grooming, dressing, and eating. Many become bedridden, contracted, develop life threatening decubital ulcers and infections. “Pneumonia followed by myocardial infarction and septicemia are the most frequent causes of death in AD” according to Forstl and Hewer (as cited in Forstl and Kruz, 1999, p. 290). The caregiver becomes responsible for total care during the final stage. This can be very overwhelming even if the person with AD is institutionalized. Most caregivers have other responsibilities besides the total care of their loved one. They have responsibilities to spouses, children, pets, careers, and community organizations. The added burden often causes animosity in the family and caregiver burnout.

### **PRIMARY CAREGIVER**

Egan, Hobson & Fearing (2006, p. 135) defined a caregiver “as all individuals who provide care and support to individuals with dementia in the community but are not paid for these services.” The connection of the primary caregiver, with the person who

has Alzheimer's, is generally a close relationship through blood or marriage. Spouses are the most common primary caregivers, especially in the age group 65 to 85. Adult children are the next most likely caregivers. Zanetti et al. (1998) reports 69% of the caregivers in their study were female (p. 361).

What is not commonly acknowledged is that caregivers represent a major and hidden part of our health care system and that unpaid care by family members is a critically important but fragile part of long-term care in the United States (Haley, 1997, p. 25S).

The primary caregiver assumes responsibility for the majority of care given to the person with AD. The major roles and challenges of the caregiver are outlined in the following section.

### **Roles and Challenges of Caregiver**

The Alzheimer's Association of the Great Plains web site (2006) reports,

Because of the disease's unpredictable course, there is no way to predict what a caregiver's role will involve. Responsibilities can include making important legal decisions, managing changes in a loved one's behavior, and helping him or her maintain hygiene. (§ 2)

The caregiving usually begins with assisting in the management of family responsibilities such as with finances, medical, and legal decisions. The caregiver is eventually responsible for providing total care. Haley (1997) reports caregivers spend an average of 60 hours per week just on caregiving alone.

Individuals with AD are unreliable sources regarding personal healthcare information; therefore the caregiver must also become the primary informant to the healthcare professionals. In this section, the caregiving roles are presented to gain a broader picture of the demands and stress faced by caregiver. These caregiving roles

include: Family; Finances, Medical and Legal; Continuum of Care; and Primary Informant.

### **Family Responsibilities**

Family responsibilities may include; 1) keeping communication lines open with extended family members, 2) tending to childcare and personal family responsibilities, 3) medication management, 4) cleaning, 5) cooking, 6) laundry, and 7) safety concerns for the individual. As the disease progresses, the caregiver takes on more responsibility for bathing, dressing, and feeding the individual with AD. One of the largest safety concerns is the day and night supervision of the Alzheimer's sufferer due to their tendency to wander and become lost. The caregiver's role becomes more demanding as the disease progresses.

### **Finances**

The caregiver's financial challenges include the loss of income by the person with Alzheimer's and/or the caregiver's income, increased living costs, and unknown future expenses. "Living standards of caregivers, and the whole family, are often lowered, sometimes greatly, by expenses for assistance with a patient with Alzheimer's disease" (Rodriguez et al., 2003, p. 331).

The loss of the income provided by the person with AD is not the only financial obstacle the family will face. The caregiver may have to discontinue paid employment to meet the increased demands of care giving. The household expenses may increase because the person with AD is no longer able to complete tasks that must then be hired out. The medical costs increase because of the increased need for medication and medical treatment as the disease process progresses.

## **Medical and Legal**

The medical and legal decisions that the caregiver faces can be emotionally and financially taxing. Acquiring the proper legal authority to make medical and financial decisions for the person with AD can be costly and confusing. Financial institutions require one kind of paperwork and medical institutions require another set. Gaining a legal power of attorney is a significant struggle for most families as well as the burden of determining who should have this responsibility within the family.

## **Continuum of Care**

As discussed prior, the day-to-day care responsibilities will increase as Alzheimer's progresses. The level of responsibility, assistance and challenge will vary depending on the needs of each individual and can include: 1) creating meaningful activities for the person with AD stimulating motivation, 2) facilitating social participation and bridging communication gaps, 3) providing transportation, 4) ensuring home and community safety, and 5) providing their personal care and hygiene. These are discussed in more detail within the following sections.

*Meaningful Activities:* Meaningful activities help to calm, occupy, and decrease the undesirable outbursts and behaviors of individuals with AD. These activities can include: exercise, reminiscence, and creative art projects provide cognitive stimulation and promote physical well being. Finding appropriate activities that are meaningful, interesting and provide just the right challenge for the individual can be an ongoing process and challenge for the caregiver. This is why caregivers often request help in this area. Motivation is difficult, due to the nature of the disease, individuals with AD often

choose not to participate. They may be afraid the activity could bring on cognitive difficulties causing unsatisfactory results. .

*Social Interactions and Communication:* Social interactions become increasingly difficult for the person with AD due to memory loss, decreased verbal retrieval skills, decreased social inhibitions and spontaneous changes in cognition. Communication gaps emerge as memory loss increases and comprehension decreases. The person with AD has difficulty communicating needs and often becomes agitated and frustrated due to the decline in ability to connect with others. (Forstl & Kurz, 1999).

*Transportation:* One of the most emotional issues in day-to-day care comes when the person is unsafe to drive. The loss of independence and personal freedom has a significant impact as does the realization that the disease is winning. Individuals, during clear cognitive times, lament the loss of their former freedom. For the caregiver this means more responsibility to get their loved one to doctor's appointments, to and from activities, to work (if the person is still working), and to other ordinary events. The person with AD is no longer able to go to the store alone to help with shopping or other small tasks that involve driving.

*Home and Community Safety:* The person with AD is at risk for causing safety hazards in the home due to memory loss or decreased cognition. The caregiver who continues to work outside the home is faced with the increased safety risks of leaving the person with AD home alone, or trying to find other options for the care of their loved one. "Household gas or electric appliances are a constant source of danger to the patients... Patients in this moderate state of illness cannot survive in the community without close supervision" (Forstl & Kurz, 1999, p. 289). In addition to home safety,

individuals with AD may become lost or confused when attempting to function independently within the community.

*Providing Personal Care and Hygiene:* Caregivers are challenged by the decline of self-care skills in their loved ones. “Patients become distractible and gradually lose insight into their condition. Longer (ideomotor) sequences of action can no longer be organized, until, finally the skills of using household appliances, dressing and eating are lost” (Forstl & Kurz, 1999, p. 289). Most caregivers have little training as they attempt to assist the person with AD during bathing, dressing, grooming and toileting tasks. These are very private / intimate issues for the person with AD and can be emotionally and physically challenging for the caregiver.

### **Primary Informant**

The caregiver is often the one to track the progression of the disease and report new symptoms to medical professionals. The caregiver becomes the informant for the medical professional by default. The focus is primarily on the individual diagnosed with Alzheimer’s and their considerable needs. The impact of the situation for the caregiver often receives less or no focus. The stress of living with and caring for a person with AD can precipitate several undesirable physical and emotional symptoms in the caregivers.

### **Impact on Caregivers**

The intense amount of energy required to provide round the clock care for person with AD can drain the caregiver’s physical and emotional reserves. Grant et al. (2002, p. 477) state “providing care for a relative with AD can be a potent source of chronic stress that can lead to deleterious consequences for both the physical health and emotional well-

being of a subset of caregivers.” The caregivers face emotional issues, psychological changes, and physical problems, which are presented, in the following sections.

### **Emotional & Psychological**

Haley (1997) suggests that 30 to 50 percent of the caregivers report experiencing clinically significant depression. Caregivers also experience changes in social behaviors, moods, and appraisals of reality. Haley reports that the mental health effects continue even after nursing home placement or death of the patient. Loos and Bowd report “guilt is deepened and emotional well-being is at risk when full-time care is transferred to an institution. Expressions of guilt are perhaps ‘the most debilitating emotions plaguing caregivers’ (Oliver & Bock, 1985, p.28, as cited in Loos & Bowd 1997, p. 511). Grant et al. (2002) state that these;

data suggest that both placement and death of the demented relative can have beneficial effects on the mood of the CG (caregiver), but that this effect can take 12 months to become evident. In both instances, it may be the case that relief from the chronic worry and emotional and physical demands of caregiving result in improved psychological status of the caregiver and that this relief outweighs whatever increase in depression might be expected from a sense of guilt over placement or loss after death. (p. 483)

Caregivers who have not developed positive coping strategies put their emotional and physical health at risk. This changes the amount and quality of care they are able to provide and thus impacts the quality of life for the person with AD. Caregivers use different ways to cope with the many pressures of care giving. “A constant support represents a crucial element in any program for Alzheimer patients and their informal caregivers, during all the course of the disease, whether patients stay at home or move in an institution” (Clovez, Joel, Ponton-Sanchez, Royer, 2002, p. 232).

Due to the increased emotional exhaustion of caregiving, many caregivers neglect to care for their own emotional and physical health. Hailey (1997) and Bullock (2004)

list the following physical effects of care giving:

1. impaired immune system function
2. elevated blood pressure
3. altered plasma lipid levels
4. poor self-care
5. relatively high use of psychotropic drugs
6. back pain
7. arthritis
8. ulcers
9. indigestion, and
10. sleep disturbances

Kiecolt-Glaser, et al., 1991(as cited in Hailey, 1997) validates information regarding the immune system in caregivers being significantly altered. The immune system alterations are being reported up to four years after the death of the person with AD. Increased blood pressure and wound healing times are some of the other reported physical manifestations resulting from the increased stress the caregiver faces.

Increased stress and lack of personal time contributes to the physical deconditioning of caregivers. Many of the caregivers are aging physically themselves and are more at risk for injury due to the physical nature of caregiving. The long hours required supervising the person with Alzheimer's leads to physical and emotional exhaustion.

In the midst of all of these factors, family members and caregivers are confronted with many tough decisions. Often family members disagree about the solutions to these important decisions and it can tear families apart. Planning for the future can take a back seat to everyday challenges and denial could mask the intense need for help. Some of the



options that can meet caregiver's emotional and physical needs as well as the needs of their loved one are described in the following section.

### **Options For Long-term Care**

As a caregiver, it is important to have long-term care plans in place. "It is extremely difficult, if not impossible, to be the sole care provider for someone with Alzheimer's through the entire process of the disease" (Petersen, 2002, p. 183). Petersen (2002) indicates caregiver hesitation to ask for help, is one of the biggest obstacles to overcome. Accepting assistance can significantly reduce caregiver burden both physically and emotionally.

Medical professionals should provide as much information and support to the families as possible. Doctors, who are aware of the support programs and services available in the community, can inform the families of community supports and therapies. Therapists, using best practice methods, can provide needed support to the families and persons with AD. Families are sometimes unaware of the valuable resources available in their local community. Getting the essential information and necessary services to the families has been a challenge in the past.

Friends and families can link the caregiver with needed services or become the family's support group. Community services like public transportation, senior centers, health programs, recreation centers, and assisted living centers can provide information or services needed by the family. Alzheimer's association meetings, local community services, church services, financial and legal services are all resources the caregiver may seek out. When the burden of caregiving becomes overwhelming, the caregiver may

realize the need for outside intervention. Professional services in the home or placement in a facility can decrease the burden of the caregiver.

### **Facility Placement**

Many communities have a number of services to assist Alzheimer's caregivers. Two important contacts for the caregiver include the local Alzheimer's Association and the local senior center. These two affiliations will have information regarding respite care available in the community, local assisted living facilities, skilled nursing facilities, and caregiver support groups.

**Respite Care:** In many communities respite care is available through the local senior center, home health care agencies, and adult daycare centers. Adult Daycare centers allow the caregiver to drop their loved one off in a caring and safe environment for the day, and pick them up in the evening. Home health care is another option that provides skilled nursing services to the individual with Alzheimer's in the home.

**Long-term Care:** The next option for caregivers may then become placement in a long-term care facility. The first level of long-term care is in an assisted living facility. "Assisted living facilities (or board and care homes) bridge the gap between living independently and living in a nursing home. Facilities typically offer a combination of housing and meals; supportive, personalized assistance; and health care services" (Alzheimer's Association of the Great Plains, 2006, ¶ 8).

**Skilled Nursing Facility:** Depending on the severity and progression of the disease, many times assisted living is not an option. Another option for long-term care is a skilled nursing facility (SNF) or nursing home. "As many as 90% of patients with

dementia reportedly become institutionalized before death” Smith, Kokmen, & O’Brien, 2000 (as cited in Yaffe et al. 2002, p. 2090). SNF provide twenty-four hour total care. Many SNF have a specialized unit within the facility for Alzheimer’s patients.

**Specialized Care:** Another option is a dementia/Alzheimer’s specialized care facility. This type of facility is a new trend in Alzheimer’s care. Long-term care facilities that specialize in Alzheimer’s care are beneficial to the patient, family, and care givers. The research shows participants living in these specialized care facilities have higher levels of cognitive and occupational functioning (Davis et al., 2000). These higher levels of functioning and quality of life are also related to the amount social contact the patient receives. Zimmerman et al. study (2005, p. 133) indicated “better resident-staff communication was related to higher quality of life...” They offer the care and socialization needed, while creating a safe and comfortable home for the residents. Although placing a loved one in a facility can be difficult and heart breaking, it provides the family with a sense of safety and the patient with the best care possible.

**Referrals:** The stress of those who care for a loved one with AD can be overwhelming. The families all too often are not offered additional supports or therapy services. This leaves the families unequipped to deal with devastating problems, which drastically affects the quality of life for those with AD and the health of the caregiver. The authors personally experienced the lack of information and support provided to the caregiver. During the authors’ occupational therapy education, they have learned of interventions and caregiver education strategies which are beneficial for both the client and the caregiver, and lighten the family’s burdens.

## **Role of Occupational Therapy**

According to American Occupational Therapy Association (1994), “Occupational therapy often consists of caregiver education and environmental adaptation to maximize functional independence, safety, and well-being of the person with Alzheimer’s disease” (Atler & St. Michel, 1996; Corcoran & Gitlin, 1991; Josephsson, 1996, as cited in Dooley and Hinojosa, 2004, p. 561). Education of the family/caregiver is a large part of the OT role.

There may be areas of need identified by the assessments that are conducted however, the caregiver and the client should determine which areas are most important. The OT collaborates with the caregiver and client to design a plan of care providing the needed support and therapeutic interventions most valuable to the family.

Occupational therapy (OT) utilizes techniques, which help to reduce the stress and improve the quality of life for both caregivers and the persons with this disease. OT provides strategies that can ease the burden of the caregivers and provide a better quality of life for the whole family such as: coping skills, motivational techniques, alternative dressing options, transfers methods, and potential environmental adaptations. The OT, working with the family, may also be able to help increase the effectiveness of the communication between the family and other medical professionals by becoming a liaison or proposing questions the caregivers could ask other professionals.

## **Alzheimer’s Toolbox: A Caregiver’s Guide**

The toolbox is based on current research literature and evidence based practice information extracted from OT journals, medical journals, and texts. Information from

occupational therapists and other professional disciplines, working with patients who have AD, was also used in the creation of the toolbox for caregivers.

The toolbox is designed to be used by:

1. Caregivers and family members who have a loved one with Alzheimer's disease
2. Hired private caregivers who provide assistance for individuals diagnosed with Alzheimer's disease. These individuals would also benefit from resources and ideas to help the individual to live a higher quality of life.
3. Caregivers in day care settings would benefit from resources and ideas to help the individual live a higher quality of life.

The goal of the Alzheimer's Toolbox: A Caregiver's Guide is to provide information that may assist with maximizing the quality of life for both the client and the caregiver. The toolbox provides information that, when used appropriately, may help to decrease stress or provide solutions for the caregiver. The toolbox is an organized booklet, which provides the information and resources in the following sections:

1. Introduction
2. Description of Alzheimer's Disease
3. Important Terms
4. Role of Occupational Therapy
5. Caregiver Challenges & Interventions
6. Home Activities
7. Community Resources
8. Future Placement Options

“Interventions aimed at delaying or preventing long-term care placement could reduce health-care tremendously and possibly improve the quality of life of patients by maintaining their independence” (Yaffe et al., 2002, 2091). Interventions or suggestions in the toolbox focus on the following:

1. Coping & Stress Management
2. Home modifications
3. Maintaining overall health for caregivers and persons with Alzheimer's disease
4. Communication techniques

5. Non-drug therapies
6. Dealing with loneliness or depression for the caregiver

### **Model & Framework**

An occupational therapy model or frame of reference provides a specific focus and direction for intervention. The occupational therapy model used in the design of the toolbox is the Ecology of Human Performance (EHP) Model. The main constructs of the model include person, context, task, and performance. Occupational therapy uses the EHP model to modify the environments and tasks to fit the individual's functional abilities within his/her context (Dunn, Brown, & Youngstrom, 2003). The product focuses on changing the person, task, or environmental variables to improve the quality of life for the person with AD.

*Person:* The person construct is focused on the person and the variables they bring to the task performance. The personal variables might include values/interests, past experiences, sensory-motor, cognitive and psychosocial skills. The toolbox includes ideas designed to maintain skills, personal preferences, interests, or include past experiences. The individual's level of functional abilities can be enhanced by proper use of the toolbox.

*Context:* "Context refers to the set of interrelated conditions that surround the person" (Dunn, Brown, & Youngstrom, 2003, p. 226). According to Dunn, Brown & Youngstrom (2003) there are two primary types of contexts, temporal and environmental. Areas addressed in the temporal context are chronological age, developmental stage, life cycle, and health status. Environmental context is the physical, social and cultural dimensions. The context can affect the successful completion of a task.

The toolbox incorporates ideas that alter the physical and social environments to facilitate successful completion of activities. The client's chronological age and health status will determine which toolbox activities or interventions are most appropriate. Altering the amount of time given to complete a task, the setting in which the task is performed or simplification of the task are all ideas used in the toolbox.

*Task:* "Tasks are objective sets of behaviors that are combined to allow an individual to engage in performance that accomplishes a goal" (Dunn, Brown, & Youngstrom, 2003, p. 225). Dunn, Brown & Youngstrom (2003) imply a person's role can be a set of chosen and meaningful tasks in which the person wants and needs to engage. The disease process alters drastically the roles in which the person with AD will participate and also the roles the caregiver will participate. The toolbox addresses some of the changes that occur such as loss of short-term memory, episodes of aggression, change in sleep patterns and misidentifications through meaningful tasks the person wants and needs to engage in.

*Performance:* Participation in tasks, within a context, is referred to as the performance construct. Individuals use their skills to select the tasks they want and need to do. Person variables and context variables determine an individual's performance range, or the number and types of tasks available to the person (Dunn, Brown, & Youngstrom, 2003). The disease increasingly limits the person's performance range. The toolbox provides some ways to maintain independence for the person with AD. It includes resources for when the caregiver needs additional support or wants to enhance their own performance as a caregiver.

## **Conclusion**

It is the authors hope to improve the quality of life for those with AD and their caregivers through the use of the toolbox of interventions, environment alterations and coping strategies. “Participation in everyday occupations of life is a vital part of human development and lived experience” (Law, 2002, p. 640). Interventions provided in the home by professional or family caregivers will allow the individual with AD to successfully remain at home for a longer period of time with less stress to them and their caregivers. Interventions properly used in the home will help the caregivers conserve energy levels, decrease stress, increase confidence and contribute to the increased self esteem of the caregivers.

The methodology used in the development of the Caregiver’s Toolbox is identified in Chapter III. Chapter IV presents an introduction to the Caregiver’s Toolbox as well as the product in its entirety. Chapter V will present a summary, the projects limitations, how to implement the project, and recommendations.



### **CHAPTER III**

### **METHODOLOGY**

The process of developing the *Alzheimer's Toolbox: A Caregiver's Guide* began with an extensive review of current literature. The literature review was conducted using several sources such as: Harley French Library, Alzheimer's Association National website, Alzheimer's Association of the Great Plains website, Casper College Library, information from OTs and other disciplines and brochures from local long-term care facilities. The topics researched included: Alzheimer's disease (AD), occupational therapy's role, treatments, caregiver challenges and interventions, role of OT, alternative therapies, home activities, community resources, and options for future placement of individuals.

The literature review indicated that although there is a considerable amount of information available regarding Alzheimer's disease, the information is neither easily accessible for caregivers nor organized in an easy to use, consumer friendly format. In addition, many terms, consistently used in the literature, were identified and found to need simplification or explanation for the average caregiver. Based upon this information, an outline was developed to identify common themes, and organize information/resources into areas identified as beneficial for the caregivers of individuals with AD.

The *Alzheimer's Toolbox: A Caregiver's Guide* is based on the Ecology of Human Performance (EHP) model and the areas of occupation in the Occupational Therapy Practice Framework: Domain and Process. The main constructs of the model include person, context, task and performance. Occupational therapy uses the EHP model to alter environments and tasks to fit the individual's functional abilities within his/her context (Dunn, Brown, & Youngstrom, 2003).

AD drastically alters the roles in which the person with AD will participate as well as the roles of the caregiver. The EHP model is chosen because the toolbox focuses on changing the person, task or environmental variables to improve the quality of life for the person with AD. The toolbox incorporates ideas that modify the physical and social environments to facilitate successful completion of activities and roles in which the person with AD needs to engage. The client's chronological age and health status will determine which toolbox activities or interventions are most appropriate. The personal variables addressed in the toolbox include ideas designed to maintain skills, personal preferences, interests, or include past experiences. The individual's level of functional abilities can be enhanced by proper use of the toolbox.

The *Alzheimer's Toolbox: A Caregiver's Guide* is designed in an easy to understand and use format. It contains the tools needed to help improve the quality of life for all involved, and provides intervention options to maintain independence for the person with AD. It includes resources for when the caregiver needs additional support or wants to enhance their own performance. The Toolbox addresses the changes in the duties the caregiver assumes due to decreased functioning of the person with AD.

Activities of daily living, financial responsibilities, home management and legal decisions are some of the areas where changes are addressed.

It is the authors hope to improve the quality of life for those who are trying to live with AD and their caregivers by providing a toolbox of interventions, environment alterations and coping strategies. The proper use of the Toolbox will allow the users to modify the specific areas or tasks most appropriate for the individual's particular situation and provide the caregiver guidance as to when additional services might be needed.

## CHAPTER IV

### PRODUCT

#### Introduction

The development of the *Alzheimer's Toolbox: A Caregiver's Guide* is based on current research literature and evidence based practice information obtained from OT journals, medical journals, texts and the authors' personal experiences. Information from occupational therapists and other professional disciplines, working with patients who have Alzheimer's disease (AD), was also used in the creation of the toolbox. The goal of the *Alzheimer's Toolbox: A Caregiver's Guide* is to provide information and resources that may assist with maximizing the quality of life for both the client and caregiver.

#### Design

The toolbox is designed to be used by:

1. Caregivers and family members who have a loved one with Alzheimer's disease
2. Hired private caregivers who provide assistance for individuals diagnosed with Alzheimer's disease would also benefit from resources and ideas to help the individual live a higher quality of life
3. Caregivers in day care settings would benefit from resources and ideas to help the individual live a higher quality of life

## Model and Framework

An occupational therapy model or frame of reference provides a specific focus and direction for interventions. The framework used in the design of the *Alzheimer's Toolbox: A Caregiver's Guide* is the Ecology of Human Performance Model (EHP).

Occupational therapy uses the EHP model to alter environments and tasks to fit the individual's functional abilities within his/her context (Dunn, Brown, & Youngstrom, 2003). The product focuses on changing person, task or environmental variables to improve the quality of life for the person with AD. In addition, the EHP model allows for interdisciplinary collaboration regarding treatment of individuals. The main constructs of the model are defined in the following sections: person, context, task and performance.

### *Person*

The person construct is focused on the person and the variables they bring to the task performance. The personal variables might include values/interests, past experiences, sensory-motor, cognitive and psychosocial skills. The *Alzheimer's Toolbox: A Caregiver's Guide* includes ideas that are designed to maintain skills, personal preferences, interests, or include past experiences. The individual's level of functional abilities can be enhanced by proper use of the information and strategies provided.

### *Context*

"Context refers to the set of interrelated conditions that surround the person" (Dunn, Brown, & Youngstrom, 2003, p. 226). The context can affect the successful completion of a task. According to Dunn, Brown, & Youngstrom (2003) there are two

primary contexts; temporal and environmental. Areas addressed in the temporal context are chronological age, developmental stage, life cycle, and health status. Environmental context consists of the physical, social, and cultural dimensions. The *Alzheimer's Toolbox: A Caregiver's Guide* incorporates ideas to alter the physical and social environments in order to facilitate successful completion of activities. The client's chronological age and health status will determine which activities or interventions are most appropriate. Altering the amount of time given to complete a task, the setting in which the task is performed and/or simplification of the task are included in the information and strategies provided.

*Task:* "Tasks are objective sets of behaviors that are combined to allow an individual to engage in performance that accomplishes a goal" (Dunn, Brown, & Youngstrom, 2003, p. 225). Dunn, Brown & Youngstrom (2003) imply a person's role can be a set of chosen and meaningful tasks in which the person wants and needs to engage. The disease process alters drastically the roles in which the person with AD will participate and also the roles the caregiver will participate. The toolbox addresses some of the changes that occur such as loss of short-term memory, episodes of aggression, change in sleep patterns and misidentifications through meaningful tasks the person wants and needs to engage in.

*Performance:* Participation in tasks, within a context, is referred to as the performance construct. Individuals use their skills to select the tasks they want and need to do. Person variables and context variables determine an individual's performance range, or the number and types of tasks available to the person (Dunn, Brown, & Youngstrom, 2003). The disease increasingly limits the person's performance range.

The toolbox provides some ways to maintain independence for the person with AD. It includes resources for when the caregiver needs additional support or wants to enhance their own performance as a caregiver.

## **Organization**

The *Alzheimer's Toolbox: A Caregiver's Guide* is organized with the following headings:

- 1) Introduction
- 2) Description of Alzheimer's Disease
- 3) Important terms
- 4) The role of occupational therapy
- 5) Caregiver challenges and interventions
- 6) Home activities
- 7) Community resources
- 8) Future placement options

Within each of these headings is information on resources and intervention ideas for:

- 1) Coping & Stress Management
- 2) Home modifications
- 3) Maintaining overall health for caregivers and persons with Alzheimer's disease
- 4) Communication techniques
- 5) Non-drug therapies
- 6) Dealing with loneliness or depression for the caregiver

Although there is considerable information currently available, it is not organized in an easy to use, consumer friendly format. The *Alzheimer's Toolbox: A Caregiver's Guide* is designed to be a helpful resource for the caregiver. The authors hope to improve the quality of life for those with AD and their caregivers by providing a toolbox of interventions, environment alterations and coping strategies. It is hoped the information will help minimize stress and/or provide solutions for caregivers.

# Alzheimer's Toolbox: *A Caregiver's Guide*



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## Introduction

You have been provided with the *Alzheimer's Toolbox: A Caregiver's Guide* by your Occupational therapist. The goal of this toolbox is to provide you with information, strategies, ideas and resources that may hopefully assist in increasing the quality of life for your loved one and you as well as other caregivers.

The toolbox is designed to be used by:

1. Caregivers and family members who have a loved one with Alzheimer's disease
2. Hired private caregivers who provide assistance for individuals diagnosed with Alzheimer's disease, would benefit from resources and ideas to help the individual live a higher quality of life
3. Caregivers in day care settings would benefit from resources and ideas to help the individual, live a higher quality of life

The information used to develop this resource has been gathered from professional journals including occupational therapy journals, texts and occupational therapists that work with patients who have Alzheimer's disease (AD).

"Most patients with dementia continue to live in the community until family caregivers are no longer able to care for them" (Rice, Fox, & Max, et al. 1993, as cited in Yaffe et al., 2002, p. 2090). As you or other caregivers increase your skill and resources, you will be able to extend quality care in the home and delay long-term care placement.

The toolbox provides information that, when used appropriately, may help to decrease stress or provide solutions for you, the caregiver. This toolbox is an organized booklet with the following sections:

1. Introduction
2. Description of Alzheimer's disease
3. Important Terms
4. Role of Occupational Therapy
5. Caregiver challenges and Interventions
6. Appropriate home activities
7. Community Resources
8. Future Placement Options

Interventions or suggestions in the toolbox include:

1. Coping & Stress Management
2. Home modifications

3. Maintaining overall health for caregivers and persons with Alzheimer's disease
4. Communication techniques
5. Non-drug therapies
6. Dealing with loneliness or depression for the caregiver

Use of the interventions and suggestions in the toolbox may assist with increasing the quality of life for both you and your loved one with Alzheimer's disease. "Interventions aimed at delaying or preventing long-term care placement could reduce health-care costs tremendously and possibly improve the quality of life of patients by maintaining their independence" (Michel, Zekry, Mulligan, Giacobini, Gold, 2001, as cited in Yaffe et al., 2002, p. 2091).

# Alzheimer's Disease



## **Alzheimer's Disease**

Alzheimer's disease (AD) is a type of dementia that worsens over time. The chance a person will get Alzheimer's disease increases as the person ages. There are many people in this country who suffer from the effects of Alzheimer's disease. It is present in 50% of the people who are over 85 years old (Reed, 2001).

The cause of Alzheimer's disease is unknown. The disease process involves deterioration of the brain and its ability to function. The disease causes a loss of memory starting with recent events and continues until it eventually destroys all memories.

According to Forstl and Kurz (1999), as Alzheimer's disease progresses, individuals commonly experience 3 to 4 stages: Pre Dementia, Mild Dementia, Moderate Dementia and Severe Dementia.

### **Pre Dementia**

Mild cognitive impairment (MCI) is a term used to describe changes in a person's memory and intellectual functioning that are greater than those typically seen in the aging process. These memory and intellectual changes often represent a transitional period between normal aging (NA) and Alzheimer's disease (AD) (Greenaway et al. 2006).

"Memory loss is the core symptom of AD and appears from an early stage in most patients..." (Kashiwa et al. 2005, p. 700). Family and friends may notice memory loss, social withdrawal or depressive symptoms up to five years before a clinical diagnosis is made.

In this stage individuals will use memory aids (daily planners, written notes and lists) to try and hide the problems they are experiencing with their memory. Individuals with Alzheimer's disease often try to avoid noisy social gatherings and busy surroundings.

### **Mild Dementia**

Mild dementia is the second stage in the progression. A diagnosis of Alzheimer's is usually made in this stage because of the increased type and number of problems that begin to occur. At this stage individuals may have periods of time where the Alzheimer's disease symptoms are decreased, in which their memory may be clear.

Difficulties with language can emerge in this stage. These language difficulties can include: the loss or difficulty with the ability to speak, write, or understand written language. The person also begins to have trouble recognizing common objects (visual perceptual problems) which can cause problems with activities of daily life. Some of the activities of daily living

can include: driving, dressing, grooming, eating, and socializing. It is not recommended an individual drive once he or she has reached the second stage because of these rapid memory changes and visual problems.

### **Moderate Dementia**

The next stage, moderate dementia, is characterized by the individual living in their past life. They sometimes try to go home to a place where they grew up as a child. They often misidentify family, friends, and strangers. In this stage, individuals lose their ability to read, write, plan, and organize. Activities with multiple steps, including using household appliances, dressing, and eating, become too difficult for the individual to perform independently.

The caregiver may notice increased behavioral changes including hallucinations in this stage. Hallucinations are false or mistaken ideas the individual perceives as real (adapted from dictionary.com). Temper tantrums and a lack of emotional control are likely to occur in this stage, and are often coupled with physical and verbal aggression regardless of the individuals past personality traits. "Aimless and restless activity like wandering, hoarding, etc., are common" (Devanand et al., as cited in Forstl and Kurz, 1999, p. 289).



Once the disease has progressed to stage three the person requires direct help and supervision to complete daily activities. Various household appliances used for cooking, cleaning, and personal grooming can pose a danger to individuals with Alzheimer's disease. The risk for falls significantly increases as their walking patterns, posture and decision making ability changes.

The strain on the caregiver significantly increases at this point; you are now caring for a loved one who has become aggressive, disoriented, restless and incontinent. Due to increased strain on the family and caregiver, this is the most common time for placement or consideration of placement in a long-term care facility. Families understandably often have a difficult time making this decision.

### **Severe Dementia**

The final stage is known as severe dementia. This stage is characterized by deterioration of language and communication skills, memory, and physical abilities. The person's ability to speak diminishes into short or single word phrases and eventually disappears. Eventually the person can no longer remember any part of his or her life.

In this stage, the person will have disrupted sleep patterns and be confused between day and night. They will need total assistance with all of their daily activities such as bathing, toileting, grooming, dressing, and eating. At this stage, many individuals become bedridden and develop deformities because they are no longer able to move or use their arms, legs and hands. They can also develop life threatening skin breakdown and infections. Pneumonia, heart attack, and infection are the most common causes of death in patients with Alzheimer's disease according to Forstl and Hewer (as cited in Forstl and Kruz, 1999).



# Important Terms



## Important Terms

This section defines terms that you will hear either by members of the healthcare team or in the information when you read about the process of Alzheimer's. The terms have been listed in alphabetical order.

**Activities of daily living or ADL** - These are activities that focus on taking care of one's own body. These activities include doing things such as: bathing, showering, bowel and bladder management (going to the bathroom), toilet hygiene, dressing, eating, feeding, functional mobility (being able to move and get around), personal device care, personal hygiene and grooming, sexual activity, sleep/rest (Adapted from AOTA, 2002, p. 630).

**Alzheimer's disease or AD**- Alzheimer's disease (AD) is a type of dementia that worsens over time. The cause of Alzheimer's disease is unknown. The disease process involves deterioration of the brain and its ability to function. The disease causes a loss of memory starting with recent events and continues until it eventually destroys all memories. In the late stages of the disease the individual loses the ability to control the muscles in the body.

**Instrumental activities of daily living or IADL** - IADL's are activities that that involve complex decision making. These activities may include: care of others, tasks related to raising children, financial management, home management, meal preparation, meal clean-up, safety procedures, emergency responses, and shopping (Adapted from AOTA, 2002, p. 631).

**Intervention** - Interventions are activities, or strategies used by healthcare professionals such as the occupational therapists. Interventions are used to help the person remain as independent as possible, for as long as possible and to prevent injury to the individual and caregivers within their environment.

**Long-term memory** - The ability to remember things in one's life over his or her entire life span. The "information stored in the brain and retrievable over a long period of time, often over the entire life span of the individual" (Retrieved November 7, 2006, from dictionary.com)

**Motor Control** - Motor control is the ability of the brain to control of muscles in the body.

**Occupation** - "Everything people do to occupy themselves, including looking after themselves...enjoying life...and contributing to the social and economic fabric of their communities..." (Law, Polatajko, Baptiste, & Townsend, 1997, p.34, as cited in AOTA, 2002, p. 632)

**Occupational Therapist** - "Occupational therapists' expertise lies in their knowledge of how to promote independence and how disease and disability can affect participation in daily activities" (AOTA, 2002). The focus is on assisting people in the completion of daily life activities that she or he finds meaningful and purposeful. Examples: dressing, grooming, bathing, meal preparation and eating, and any other individualized daily activities.

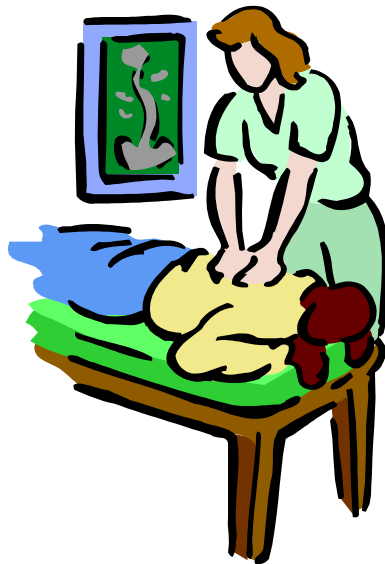
**Primary Caregiver** - Persons who care for and provide support to individuals with Alzheimer's disease. They are typically spouses, adult children and other family members (Egan, Hobson & Fearing, 2006).

**Quality of Life** - A person's perception and satisfaction with his or her life and their goals which includes: self-concept, health, daily functioning and

socioeconomic factors (e.g., vocation, education, income) (adapted from Radomski, 1995; Zhan, 1992, as cited in AOTA, 2002, p. 633).

**Short-term memory** - The "information retained in the brain and retrievable from it over a brief span of time" (Retrieved November 7, 2006, from dictionary.com).

# Role of Occupational Therapy





## Occupational Therapy

Your occupational therapists can help you in many ways and knows that you are a very important part of the intervention process. The occupational therapist teams up with you, the caregiver and your loved one to design a plan of care that provides the support you both need and therapeutic interventions that are the most valuable to the family. The Occupational Therapist's can help you by:

- Providing you with information and education on:
  - Skills that can help you cope with the stress
  - Ideas on how to motivate your loved one to get and stay involved in daily tasks and to help keep you motivated
  - Ideas to help make getting dressed and undressed easier
  - Ways to help transfer your loved one into bed, into a bath, into a wheelchair or wherever they may need to go
  - Ideas to adapt your home to make it easier for you and your loved one to get around safely and do the tasks that need to be done
  - Ideas for home activities that are appropriate meaningful and enjoyable
- Working with families to create a home environment that is therapeutic and successful for the individual with Alzheimer's disease

- Assessing the level of independence your loved one has in many areas such as: dressing, eating, bathing, memory, and safety in the home. Once this level is determined, the occupational therapist can provide ideas, suggestions and resources to help the person remain as independent as possible.
- Assisting you and your loved one by helping you communicate with other medical professionals or by proposing questions caregivers could ask other professionals.
- Providing positive reinforcement, encouragement and support
- Connecting you with others who are or have faced similar challenges.



# Caregiver Challenges and Interventions



## Caregiver Challenges

The challenges you face as a caregiver are numerous. Everyone has different ways to cope with the many pressures of care giving and some of these are effective and helpful but some are not. Using positive coping strategies can improve the quality of life for both your loved one and you, the caregiver. The next several pages list some of the challenges you could be facing and ideas to help deal with those challenges.



### Resources used for this section are:

- The Alzheimer's Association of the Great Plains Web-site
- The Book Mayo Clinic on Alzheimer's Disease by Petersen (2002)
- Corcoran, M.A. (2002, November). Occupational therapy intervention for persons with dementia and their families
- Authors personal experience

## Emotional & Psychological Challenges

You are experiencing many different feelings/emotions during this period in your life. Sometimes it can feel like a roller coaster. You will feel joy, sadness, and anger and there may be times when all of these feelings happen in a matter of minutes. The emotional challenges caregivers face and strategies to help deal with these challenges are presented in the following:

- **To help prevent or deal with feelings of Loneliness**
  - Continue regular contact with your personal friends. You need a break and the support from others is important
  - Attend a support group where you can learn other strategies and resources by people who are or have experienced these emotional feelings
  - Ask for help (family members, friends, neighbors, community services are all resources). The majority of people want to help, they just don't know how unless you ask.
  - Arrange regular times for visits from family and friends



- **To help prevent or deal with feelings of Depression**
  - Schedule time for yourself doing something you enjoy (reading, writing, crafting, exercise, visiting with friends, hobbies). Schedule at least two hours a week. This time could be coordinated with rest times or therapy sessions for the person with Alzheimer's disease. If not possible, contact a family member, friend, or local respite care service to care for the individual with Alzheimer's disease. It is much harder to function and be there for others when you do not take care of yourself.
  - See your doctor for regular check-ups to make sure you are keeping yourself healthy
  - Eat well-balanced meals and exercise regularly
  - Get a minimum 6 to 8 hours of quality sleep
  
- **To help prevent or deal with feelings of Isolation**
  - Schedule time to meet with friends
  - Ask someone to call and check on you regularly
  - Join a support group for caregivers
  - Attend activity groups that are of interest to you and the person with Alzheimer's disease (exercise, hobby, lecture, church)
  - Ask someone to assist when attending social functions, so you can enjoy the function and not be overly stressed

- **To help deal with feelings affected by the Mood Changes of the person with Alzheimer's disease**

- Strive for calm and use an accepting emotional tone
- Redirect the person's behaviors or use work that can distract them to something more positive
- Be firm, kind, flexible, and creative
- A negative tone can contribute to emotional / behavioral disturbances in the person with Alzheimer's disease
- Take a break - if you are getting frustrated make sure the person with Alzheimer's disease is safe and remove yourself from the room for a time to recover your composure.
- Don't argue with the person with Alzheimer's disease - take a break if you need to, walk away, clear your thoughts
- Play music they enjoy and find relaxing
- Approach with calmness and reassurance
- Reduce surrounding stimulation
- Remove dangerous objects from the area
- Do not pressure the individual or make additional demands



- **To help prevent or deal with Emotional Exhaustion**
  - Take care of yourself
  - Ask for help
  - Maintain a positive attitude, find something to enjoy everyday: call a friend, smell the flowers, watch the sunset, watch your favorite television show, look on the bright side
  - Laugh often - this is an emotional and physical way to help keep you healthy. Keep your sense of humor, call a friend and exchange funny stories and jokes
  - Take a nap -rest can help to rejuvenate you. Take advantage of times when the individual with Alzheimer's disease is resting.
  - Accept and move on -, dwelling on the negative will not change the situation for the better. Turn to spiritual support, implement daily positive affirmations, and identify something positive from each experience.





## Physical Challenges

Many days, a caregiver has to put in a lot of hours as she or he helps the person with Alzheimer's disease. These long days can lead to physical and emotional exhaustion. Many of the people who provide care are also aging physically and are more at risk for injury due to the amount of work it can take when caring for someone. The following are physical challenges a caregiver of a person with Alzheimer's disease could face especially if you don't take care of yourself and utilize your resources (Hailey, 1997; Bullock, 2004):

- Impaired immune system function- you could get sick more often and require a longer time to heal,
- Elevated blood pressure- this can increase your risk for stroke and heart attack,
- Indigestion and ulcers- these can be created by sudden weight changes, improper nutrition, stress and anxiety
- Sleep disturbances/physical exhaustion- you might not be able to get a good nights rest which can affect daily caregiving
- Back pain- could be caused by increased lifting and over use when assisting your loved one with daily activities like dressing, bathing, or even moving from one place to another
- Poor self-care due to increased caregiving responsibilities can lead to decreased self-esteem and illness, for example improper eating habits, lack of sleep, decreased showering or bathing, not styling hair, or wearing old clothes
- Relatively high use of psychotropic drugs used for depression

On the following pages we have included strategies to help eliminate or minimize the physical challenges.

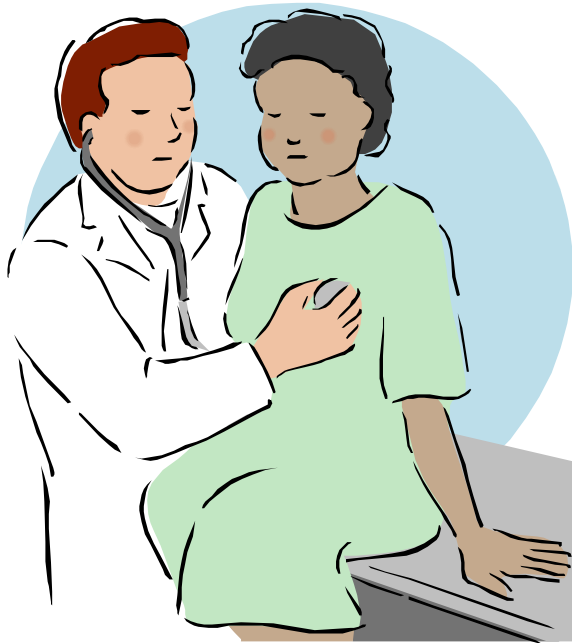
**Impaired immune system, elevated blood pressure, ulcers, indigestion, physical exhaustion**

- Regular check-ups with your doctor
  - Take regular breaks away from care giving
  - Regular exercise - this will increase endurance, improve strength, and reduce likelihood of injury and sickness. Exercising with friends can provide multiple benefits.
  - Eat well-balanced meals -Meals from local meals-on-wheels programs or senior citizen centers are balanced and decrease meal time stress on caregiver. Local restaurants are also available resources, if the budget allows.
  - Take prescription medication properly - use proper schedules and be aware of possible interactions with over the counter medications.
- **Back pain**
    - Avoid strains from over lifting or moving heavy objects - keep your back straight and lift using leg muscles.
    - Divide one heavy load into two smaller loads- one bag of groceries into multiple bags.
    - Get a massage, trade massages with a friend (if professional massage is not in the budget)

- Strengthen back and abdominal muscles during regular exercise - refer to exercise section of home activities on page 41 of the caregiver's guide.
- **Poor self care**
  - Take time for yourself - you will give better care if you take care of yourself - take time to prepare yourself for the day (shower, comb and fix your hair, or put on your make-up).
  - A regular routine is good for you and for the person with Alzheimer's disease - include time to take care of you in the routine - create a written schedule of daily events (meals, naps, and weekly activities).
  - Keep a regular hair appointment, barber shop, or salon visit.
  - Simplify as many daily tasks as possible to reduce stress - prepare double portions and freeze one part for a fast and easy meal, clean one room each day, keep household supplies where they are used (store extra bed sheets in the room where they are used, leave a set of cleaning supplies in each bathroom) See if you qualify for home delivered meals program.
  - Give yourself credit; you deserve a pat on the back because care giving is a difficult task.

- **Sleep Disturbances**

- Practice relaxation before going to bed - soft music, clear your mind; systematically relax muscles from top of head to bottoms of feet.
- In the end stages, separate beds and/or rooms maybe necessary for caregivers to get proper rest.
- Use a nursery monitor to provide safety for the person with Alzheimer's disease. Use of these devices can notify you of any problems.
- There are also door alarms that can be installed
- Regular aerobic exercise during the day will increase your ability to sleep at night - be sure to check with your physician prior to starting an exercise program.



## Communication Challenges

As the disease progresses, communication becomes more difficult.

Alzheimer's damages the pathways in the brain that makes it more difficult to find the words to say and to understand words said. Loss of communication skills such as talking, reading and writing are one of the most upsetting and frustrating parts of this disease.

Your loved one is going to have just as much trouble understanding your words as you do understand his or hers. Sometimes one word is incorrectly substituted for another, a new word is invented or she or he may just keep repeating the same word over and over. People with Alzheimer's may also (Mayo Clinic 2006, p.1):

- Lose their train of thought
- Struggle to organize words logically
- Need more time to understand what you are saying
- Curse or use offensive language

All of this can result in misunderstandings, which leads to frustration for both of you. Both positive and negative "behavior often becomes the way people with Alzheimer's communicate their feelings and needs to others" (Peterson, 2002, p. 179).



The following are examples of challenges the person can have with communication as well as suggestions on how to help the person communicate with you during the **mild to moderate stages** of the disease:

If the person:

- **Has difficulty understanding directions:**
  - Use short phrases with concise words (no more than 4 words) conveying only one message or thought
  - Give directions one step at a time
  - Ask one simple question at a time
  - Decrease environmental distractions (example: turn off background noise, avoid clutter in the work environment)
- **Repeats or invents words/stories:**
  - Be patient and listen to their stories
  - Distract the individual with another activity
  - Avoid criticizing, correcting, and arguing
- **Frequently loses their train of thought(s):**
  - Be an active listener
  - Give visual reminders
    - Example: signs with tasks broken down into single steps.  
Place signs at eye level on non-cluttered surfaces.
    - Example: placemats with pictures of proper dish arrangement

- Example: Written daily schedules placed on the kitchen table
- Give verbal reminders (example: "you were speaking of")
- Use nonverbal communication such as pointing, facial expressions and physical directions (Example: guiding the person by the hand or shoulders)
- **Tends to speak less often and rely on nonverbal gestures:**
  - Encourage the individual to participate in frequent conversations
  - Encourage the person to continue to express thoughts even if he or she is having difficulty
  - Be calm and supportive and try not to interrupt
  - Use a pleasant positive tone
  - Be patient and allow enough time for the response while the individual is communicating
  - Avoid using negative statements and quizzing (e.g., "You know who that is, don't you?")
  - Don't talk about the person as if he or she wasn't there

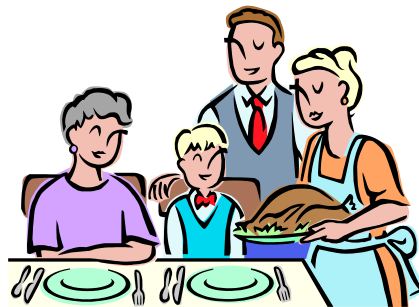
#### **Other Suggestions**

- Avoid distraction and noise so there is no competing sights and sounds when trying to talk
- Don't interrupt; it may take several minutes for him or her to respond. Avoid criticizing, hurrying correcting or arguing.

## Day-to-Day Care Challenges

The challenge of providing day-to-day care can be overwhelming. Most caregivers have little training on how to help the person with daily activities including: bathing, dressing, grooming and toileting tasks. These are very private / intimate issues for the person with Alzheimer's disease and can be emotionally and physically draining for the caregiver.

Individuals with Alzheimer's disease in the mild to moderate dementia stage lose their ability to use household appliances and complete daily tasks. The caregiver must supervise and assist their loved one with most activities. Creating a structured daily routine will decrease client anxiety and caregiver burden.







**Ideas to assist with Dressing:**

- Label drawers with contents - use as few words as possible and/or use a picture
- Keep closets clutter free - remove clothes that are undesirable
- Hang clothes that are worn together on the same hanger
- Lay out clothes for after bath or shower
- Simplify clothing as needed (use slip on shoes or Velcro closures for shoes, pullover shirts, elastic waist pants, coveralls, slip on house dresses, etc.)
- Leave written messages that suggest what activity to do next (for example, Shower, dress and meet in the dining room for breakfast) If this is your loved one you can include "love, \_\_\_\_\_" or other words of love. Take advantage of this time to leave love notes, their memory maybe going but their feelings aren't.

- **Ideas to assist with Bathing, Showering, Grooming, Hygiene**

- Have all supplies close at hand - baskets work well for this
- Simplify activity - try handing supplies to person as needed, avoid clutter
- Check water temperature before they enter bath or shower. Consider purchasing a temperature regulated shower or faucet head.
- Use shower or bath chair with hand held shower head if balance or endurance is an issue
- Give short verbal cues (suggestions) as to next step - Allow the person to do as much as they can on their own, give cues where needed

- **Ideas to assist with Toileting**

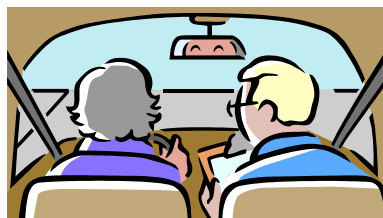
- Provide regular opportunities to use the bathroom
- Provide large clear signs that point to bathroom
- Inside the bathroom provide picture chart with steps for completing task
- Clothing with elastic waists or easy close fasteners will make the task less complicated

Incontinence of bladder and bowel will become more frequent as the disease progresses, prepare for accidents by having an extra set of clothing handy, disposable briefs maybe an option as frequency of incontinence increases.

- **Ideas to assist with Driving**

**For most people driving is a necessity as well as a sign of independence. It's hard to give up your independence by giving up your keys to your car.**

- Discuss driving privileges early in the disease process to lessen the distress when driving is no longer safe, accidents or getting lost become more frequent as the disease progresses
- Plan trips (during early stage of disease) during low traffic times and along familiar, uncomplicated routes for best success
- Having another person navigate or assist with directions / memory lapse will improve driving success in the early stages
- Request an occupational therapy driving evaluation to determine a safe time to stop driving.
- During and after the middle stage of the disease, driving is not recommended due to memory loss and decreased decision making skills
- Give the person with Alzheimer's disease the challenge to look for landmarks while traveling (let me know when you see the grocery store, or the park near our house, etc)



- **Ideas to assist with Financial and Legal Matters**
  - Loss of income for the person with Alzheimer's disease and/or the caregiver will be a consideration for budgeting expenses, it may be necessary to apply for financial assistance through government agencies like social security disability, food stamps or use retirement savings.
  - Legal power of Attorney for medical and financial matters should be addressed early in the disease process
    - A lawyer familiar with senior or family law can assist with this
  - Estate planning and living will should be updated, the person with Alzheimer's disease will not be able to manage his or her finances and legal affairs
  - Social Security, Medicare/Medicaid, and insurance issues will require specific paperwork and/or verbal permission for completion - there are qualified case managers who can help assist you with these issues or you can contact the department of family services in your area.



# Home Activities





## Home Activities

Home activities can help calm, occupy, and decrease the undesirable behaviors of individuals with Alzheimer's disease such as anxiety, aggression, agitation and restlessness. Activities such as music, exercise, reminiscence, and creative art projects provide brain stimulation and promote physical well being.

It is important to find appropriate activities that are meaningful, interesting and provide just the right challenge for the individual with Alzheimer's disease. The following section includes ideas/suggestions of activities for music, exercise, reminiscence, and creative art that can be included in your daily routine.

**The suggested activities adapted from:**

FitzRay, B.J. (2001). *Alzheimer's Activities: Hundreds of Activities for Men and Women with Alzheimer's Disease and Related Disorders*. Windsor, CA: Rayve Productions Inc.

## Musical Entertainment

Music activities can provide stimulation and promote social interaction while having fun. Singing, dancing, playing instruments, and listening to music can be a means of self-expression for both you and the individual with Alzheimer's disease. Music activities can have a calming effect on the following symptoms: anxiety, agitation, restlessness, depression, withdrawal, disorientation, rapid mood changes, short- and long-term memory, and language difficulties (Bortons and Marti 2003).

### Recommended Music Activities

- **Listen to Favorite Music:** Keep a portable stereo available so the individual with Alzheimer's disease (AD) can take their music anywhere.
- While playing the person's favorite music:
  - **Dance:** Do not let mobility impairments get in the way. Individuals with walkers and wheelchairs can move to the beat and rhythm of the music while sitting
  - **Have a Sing-a-long:** Sing familiar songs with the person.
  - **Play a musical Instrument:** If the person with Alzheimer's disease played a musical instrument in the past, assist them to continue to play. If not, use some hand held instruments (drums or tambourines) to play along with the radio.

## Exercise Activities

Exercise can be used in all stages of Alzheimer's disease (AD). "For individuals with dementia, exercise programs are particularly likely to improve health, mood, and quality of life..." (Logsdon, McCurry, Teri, 2005, p. 90). Regular exercise for both the individual with Alzheimer's disease and the caregiver will regulate the body and maintain muscle function. Exercise may also help reduce impatience, anxiety, and aggressive behavior. **Be sure to consult your physician before both of you start a regular exercise routine.**

## Recommended Exercise Activities

- Take a short walk
- Put on some music and dance
- Go window shopping at the local shopping mall
- Watch and participate in an easy-to-do exercise video or an exercise television show
- Go for a swim
  - Many recreation centers offer classes for senior citizens
- Light weight Lifting
  - Using a 1 to 2 pound canned food product that is easy to hold.
  - Many senior centers offer classes for senior citizens
- Yard Work
  - Sweep the walkways or rake leaves
  - Supervise lawn mower use
  - garden
- Clean the house
  - Have the individual with Alzheimer's disease assist the caregiver with dusting, vacuuming, and sweeping



## Let's Reminisce

Reminiscence allows the individual with Alzheimer's disease (AD) to share and remember important events of their life with the caregiver and other family members. Reminiscence can be used to promote self esteem, identity, and communication among individuals with Alzheimer's disease. Through reminiscing the individual is reminded of their family and life accomplishments.

### Recommended Reminiscence Activities

- Make a family scrap book
  - Include name labels for each picture to reinforce name memory and face recognition
- Make a home movie of family gatherings
- Reminisce about family members and tell family stories
- Reminisce about past work history
- Reminisce about hobbies
- Watch old home movies, videos, or slides and discuss the individuals in the pictures
- Create a memory box including family photos, trinkets, personal collections, or any other items the individual would like to include.
  - Have the individual decorate his/her box if she or he can
  - Spend time each week talking about the items in the box.



## Creative Art Projects

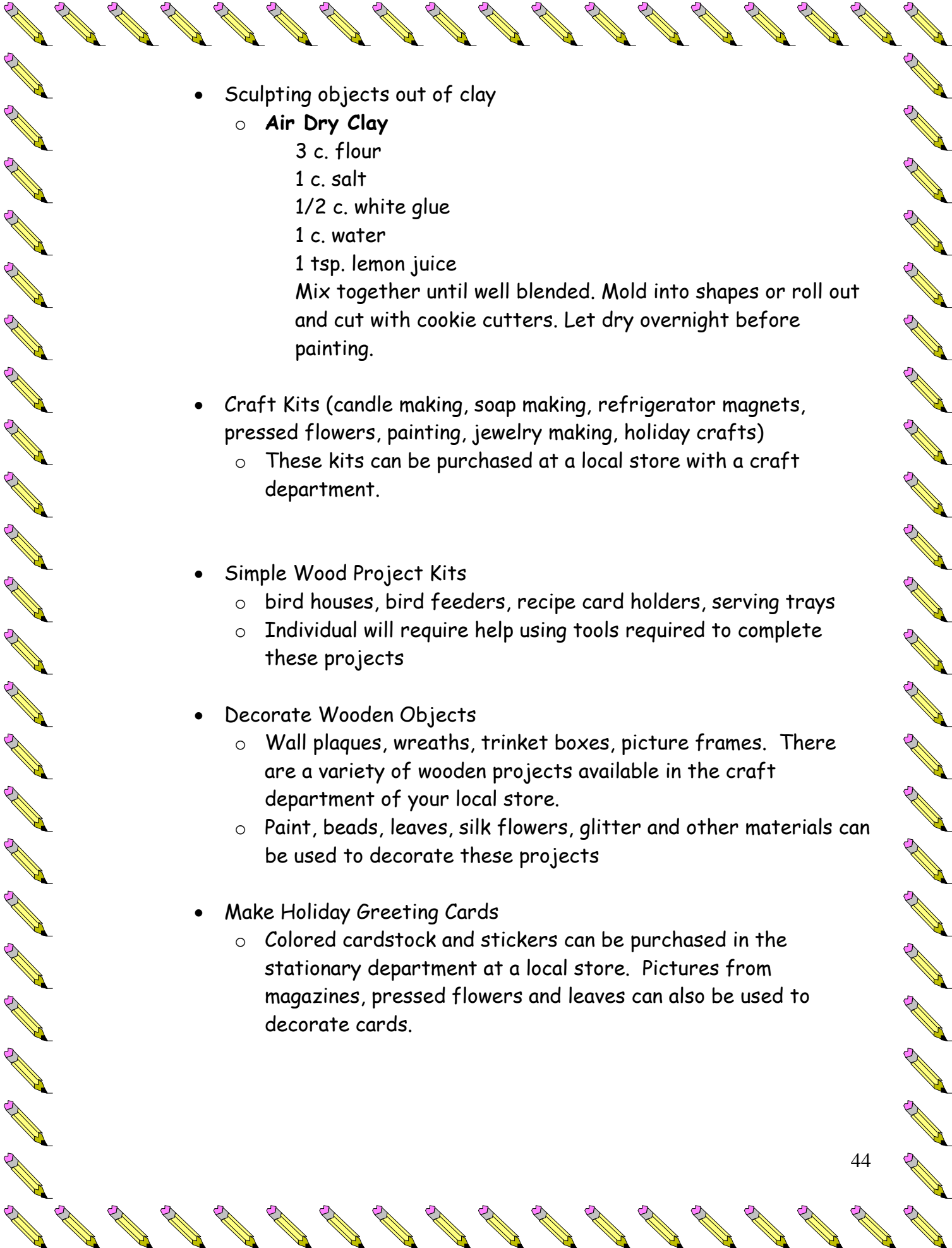
Art projects provide a means of self expression for the individual with Alzheimer's disease (AD). The use of arts and crafts can also be used to promote socialization and increase feelings of self-accomplishment. There is a wide range of arts and crafts that can be used with Alzheimer's disease. The caregiver can purchase pre-made craft kits or provide the individual with supplies to create an individualized project. Persons with past art experience and talent should be encouraged to continue using that talent with the help of adaptation from the caregiver.

- ★ Be sure to note the number of steps required to complete the task; projects with one to two step tasks will be the most successful. The caregiver will need to give instructions for the project one step at a time.

## Recommended Arts and Crafts Activities

**Choose something that interests the person, is meaningful and age appropriate**

- Purchase a variety of crayons and coloring books with pictures that appeal to the individual with Alzheimer's disease
- Purchase some water color paints and watercolor paper to paint a free hand picture
- Collage Placemats
  - Collect pictures of interest from magazines and glue them onto poster board to make placemats.
  - Family photos could also be used to create placemats
  - Create a table setting placemat using pictures of plates, cups, and silverware to enhance table setting ability.
- Decorating Sugar Cookies
  - Pre-cut sugar cookie dough to bake can be purchased at a local grocery store.
  - Provide a variety of decorating items

- 
- Sculpting objects out of clay
    - **Air Dry Clay**
      - 3 c. flour
      - 1 c. salt
      - 1/2 c. white glue
      - 1 c. water
      - 1 tsp. lemon juiceMix together until well blended. Mold into shapes or roll out and cut with cookie cutters. Let dry overnight before painting.
  - Craft Kits (candle making, soap making, refrigerator magnets, pressed flowers, painting, jewelry making, holiday crafts)
    - These kits can be purchased at a local store with a craft department.
  - Simple Wood Project Kits
    - bird houses, bird feeders, recipe card holders, serving trays
    - Individual will require help using tools required to complete these projects
  - Decorate Wooden Objects
    - Wall plaques, wreaths, trinket boxes, picture frames. There are a variety of wooden projects available in the craft department of your local store.
    - Paint, beads, leaves, silk flowers, glitter and other materials can be used to decorate these projects
  - Make Holiday Greeting Cards
    - Colored cardstock and stickers can be purchased in the stationary department at a local store. Pictures from magazines, pressed flowers and leaves can also be used to decorate cards.

# Community Resources



## Community Resources

Many communities have a number of services that can help you. Two important contacts for you include the local Alzheimer's Association and the local senior center. Caregivers often hesitate to ask for help, which is one of the biggest obstacles to overcome (Petersen, 2002). Accepting assistance can significantly reduce the burden on you both physically and emotionally.

This section provides information on general resources. You can find information on local resources in the telephone book; asking your physician, and/or by contacting your local senior center. Primary resources include:

1. The Alzheimer's Association can provide you with education and support. Many local chapters of the Alzheimer's association sponsor educational workshops for families and caregivers and can help you find additional resources. To locate a local chapter look in the telephone book or contact the national association at:

- 1-800-272-3900
- <http://www.alz.org> (internet)

2. Your local senior center will have information regarding Alzheimer's support services in the community.

- a. Many senior centers also offer caregiver education and support groups.
- b. Senior centers also many exercise classes and craft groups for clients and caregivers.
- c. Local physicians and health clinics can also be great resources. They can address medical needs as well as make referrals to beneficial services like occupational therapy.

3. Adult daycare centers are an excellent resource for the caregiver.

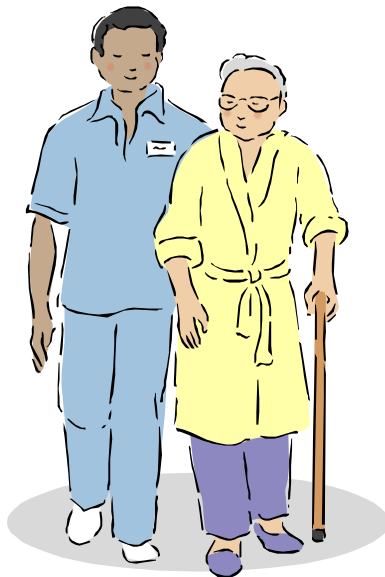
Adult daycare centers allow the caregiver to drop their loved one off in a caring and safe environment for the day and pick them up in the evening. Adult daycare centers have:

- a. Programs that offer services to physically or mentally impaired adults.
- b. Help individuals with Alzheimer's disease to remain in the community as long as possible.
- c. Provide constant supervision and assistance with daily activities including: toileting, bathing, dressing, and eating.
- d. Often provide care for both private paying residents and residents covered by Medicaid.

• **Common Services Provided by Adult Daycare Centers Include:**

- ADL Assistance and Medication Reminders
- Total Supervision
- Socialization
- Meals and Snacks
- Game, Craft and Exercise Groups
- Caregiver Education and support
- Outdoor activities
- Transportation

# Future Placement Options



## Future Placement Services

As a caregiver, it is important to have long-term care plans in place.

"It is extremely difficult, if not impossible; to be the sole care provider for someone with Alzheimer's through the entire process of the disease"

(Petersen, 2002, p. 183). The options for future placement include: home health care, assisted living, skilled nursing facility (SNF), dementia specialized facilities. Each of these facilities is discussed in more detail with a description of each and the common services. These descriptions can be used by comparing the list of services offered, to the areas in which your loved one needs assistance.





## **Home Health Care Services**

Home healthcare is a service that provides skilled nursing to an individual in their own home. These healthcare providers are usually certified nursing assistants or registered nurses that work for a home health agency. The healthcare provider will come to your home and help with daily activities such as: toileting, bathing, dressing, and eating. Home healthcare agencies provide care for both private paying clients and clients covered by Medicare. However, clients must be considered homebound (unable to leave the home) in order for Medicare to cover the cost of services.

Services will vary with each home healthcare agency.

### **Common Services Provided by Home Healthcare:**

- Skilled Nursing
- Medication management
- Activities of daily living (ADL) assistance
- Caregiver education on care management and coping strategies
- Respite Care

### **Medicare Guidelines for reimbursement:**

- Homebound
- Skilled nursing is required
- Care is provided in the client's place of residence
- Certified home health agency provides care

## Assisted Living Facilities

Assisted living is designed for people who want the privacy of their own home with the security of 24 hour Care. Assisted living facilities provide a safe environment for individuals who can no longer live at home alone but do not need skilled nursing care. This setting promotes independence among those who require assistance with daily activities but not intensive medical care. Some of these daily activities include: bathing, grooming, dressing, meal preparation, medication management, transportation, and various social and leisure activities. Depending on the severity and progression of the disease, many times assisted living is not an option. Assisted Living Facilities provide care for both private paying residents and residents covered by Medicare/Medicaid.

- **Services Provided will vary with facility but could include:**
  - Private room including a bathroom, kitchenette, and climate control.
  - Three meals a day served in a communal dining room.
  - 24 hour skilled nursing care
  - Assisted bathing and dressing as needed
  - Emergency Call systems in each room and bathroom
  - Coordination with other health care providers
  - All utilities and apartment maintenance are included with monthly rent.
  - Weekly laundry service
  - Medication Management and some medication supervision
  - Transportation to various activities and doctors appointments
  - On site beauty shop
  - Various activities and social events planned daily

Services will vary with each assisted living facilities.

## **Skilled Nursing Facilities**

Skilled nursing facilities (SNF), commonly referred to as nursing homes, are residential facilities for all persons with chronic illness, disability, or psychological illness. Many nursing home residents are elderly and require constant medical care and twenty-four hour supervision. These individuals are dependent upon a caregiver and need assistance with all daily activities. Most SNF have a mixture of residents of various ages and who have a variety of medical conditions. Many SNF have a specialized unit within the facility for Alzheimer's patients. SNF provide care for both private paying residents and residents covered by Medicare/ Medicaid.

- **Common Services Provided at SNF:**

- Three meals a day
- 24 hour skilled nursing care
- Assisted bathing, walking, eating and dressing as needed
- Administration of medication
- Emergency Call systems in each room and bathroom
- Locked doors to protect wandering residents
- Coordination with other health care providers
- Transportation to various activities and doctors appointments
- On site beauty shop
- Various activities and social events planned daily
- Alzheimer's Care

- **Rehabilitation Services Offered**

- Occupational Therapy
- Physical Therapy
- Speech Therapy

Services will vary with individual SNF.

## **Dementia / Alzheimer's Specialized Care Facility**

One other option is a dementia/Alzheimer's specialized care facility. This type of facility is a new trend in Alzheimer's care, so there are not many in operation at this time. These facilities are often small and have a home-like environment. Staff training is the key component in these specialized facilities. The staff understands dementia/Alzheimer's and the symptoms and behaviors that come with it. Long-term care facilities that specialize in Alzheimer's care are beneficial to the patient, family, and care givers. These facilities provide care for both private paying residents and residents covered by Medicare/ Medicaid.

- **Services Offered at these specialized facilities include:**
  - Three meals a day
  - 24 hour skilled nursing care
  - Educated staff
  - Small, Home like environment
  - Fewer Residents
  - Assisted bathing, walking, eating and dressing as needed
  - Administration of medication
  - Emergency Call systems in each room and bathroom
  - Locked doors to protect wandering residents
  - Coordination with other health care providers
  - Transportation to various activities and doctors appointments
  - Various activities and social events planned daily
  - Family and caregiver education and support
  - Exercise groups

Services will vary with each individual facility.

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## CHAPTER V

### SUMMARY

Approximately 4.5 million Americans suffer from Alzheimer's and their caregivers are suffering right alongside their loved one. They are suffering the slow loss of a spouse, parent, and/or companion as well as the loss of their life, as they planned it, with this individual. According to Rodriquez et al. (2003, p. 329) "from the emotional point of view, caregivers claim loss of free time, friendships, and hobbies, and feel isolated in the social context: sometimes the patient's death is thought of as a solution."

The intense amount of energy required to provide round the clock care for person with AD can drain the caregiver's physical and emotional reserves. Grant et al. (2002, p. 477) states "providing care for a relative with AD can be a potent source of chronic stress that can lead to deleterious consequences for both the physical health and emotional well-being of a subset of caregivers." The caregivers face emotional issues, psychological changes, and physical problems. Haley (1997) suggests that 30 to 50 percent of the caregivers report experiencing clinically significant depression. Caregivers also experience changes in social behaviors, moods, and appraisals of reality.

Caregivers who have not developed positive coping strategies put their emotional and physical health at risk. This changes the amount and quality of care they are able to provide and thus impacts the quality of life for the person with AD. Caregivers use

different ways to cope with the many pressures of care giving. “A constant support represents a crucial element in any program for Alzheimer patients and their informal caregivers, during all the course of the disease, whether patients stay at home or move in an institution” (Clovez, Joel, Ponton-Sanchez, Royer, 2002, p. 232).

The authors’ personally experienced the lack of information / support provided to the private caregiver and believes the toolbox's contents could change lives for the better. A comprehensive literature review was conducted to explore and identify effective techniques and interventions, which are pertinent to the quality of life for both the caregiver and the person with Alzheimer’s disease. The findings from the literature assisted in the development of the *Alzheimer’s Toolbox: A Caregiver’s Guide*.

The Toolbox incorporates interventions focusing on changing the person, task or environmental variables to improve the quality of life for the person with AD and ease some of the challenges of the caregiver. The Toolbox contains general ideas and interventions to be used by caregivers. Each person with Alzheimer’s disease has different specific needs and each caregiver has limited skills and/or resources.

### **Proposed Implementation**

This project could be implemented as a resource for OT students during their course of schooling. The project would help students gain a better understanding of AD, the role of an AD caregiver, and suggestions and recommendations they could give as an occupational therapist. This project could also be utilized by occupational therapists who need information regarding AD, caregiver education, and possible recommendations.

## **Conclusions, Recommendations and Limitations**

1. The Toolbox contains general ideas and interventions to be used by caregivers. Each person with Alzheimer's disease has different specific needs and each caregiver has limited skills and/or resources.
2. The toolbox cannot address, eliminate, or reduce every problem experienced by this wide and varied audience. The hope is that the Toolbox will provide enough general information or resources for the caregiver to access sufficient support to meet their various needs.
3. One limitation of this Toolbox is the cost of producing the product. Grant funding or foundation funding could be obtained to provide printing and binding costs.
4. As the product is mass-produced the cost per booklet will decrease. It is recommended that double-sided printing be used to decrease the cost of product.
5. The Toolbox is designed to stand-alone and provides information and resources to the caregivers. The preferred method of distribution to families or caregivers is through local physician's offices, senior citizen centers, Alzheimer's support groups, long term care facilities and local occupational therapists.
6. It is recommended that this tool be distributed for six months on a citywide basis with a short outcome based survey. If at the end of the period the results of the survey indicate significant improvement in the lives of the caregivers or the person's with Alzheimer's disease then a wider distribution should be established

It is the authors hope to improve the quality of life for those who are living with AD and their caregivers by providing a toolbox of interventions, environment alterations and coping strategies. The proper use of the Toolbox will allow the users to modify the specific areas or tasks most appropriate for the individual's particular situation and provide the caregiver guidance as to when additional services might be needed.

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