An educational resource forum for family caregivers of individuals with Alzheimer's disease

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AN EDUCATIONAL RESOURCE FORUM FOR FAMILY CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER’S DISEASE

by

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This Scholarly Project Paper, submitted by Tina Langlie and Karli Morman 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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Title An educational resource forum for family caregivers of individuals with Alzheimer’s disease

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ABSTRACT

There are currently 10 million Americans who care for a loved one with Alzheimer’s disease or another form of dementia (Alzheimer’s Association, 2008). Monitoring and maintaining the health of the caregiver is important because it allows the individual with Alzheimer’s disease to remain in their familiar home environment for as long as possible. It has been proven that both physical and emotional health of a caregiver decline with the demands associated with caregiving (O’Rourke, Cappeliez, & Neufeld, 2007). Healthcare professionals are responsible for assisting caregivers with maintaining their own health while caring for their loved one. Therefore, it is important to develop and implement health education directed toward a caregiver to promote their overall health and well-being.

A review of the literature revealed that emotional and physical health of a caregiver is negatively impacted with the increased demands associated with caregiving (O’Rourke et al., 2007). Demographic differences including gender, age, race, premorbid relationship satisfaction, education, and income all are found to affect the experience felt by the caregiver. A variety of interventions including education, psychoeducation, supportive therapy, respite care, psychotherapy, and multicomponent approaches have been shown to be beneficial to the caregiver population and have been useful in decreasing burden and in improving overall health and well-being.

This educational resource forum was designed to maintain or improve a caregiver’s physical and emotional health enabling them to adequately care for their
loved one for as long as possible. The forum used an interdisciplinary, multicomponent approach and incorporated education, psychoeducation, supportive therapy, and community resources into the interactive six-session course. Future plans consist of pilot testing and implementation of this educational series into community settings within the region.
CHAPTER I
INTRODUCTION

Alzheimer’s disease is rapidly becoming more prevalent throughout the United States. In the year 2007, it was shown that 5.1 million individuals in the United States were diagnosed with Alzheimer’s disease and every 72 seconds another individual was diagnosed (Alzheimer’s Association, 2007). It is predicted that by mid century, every 33 seconds a new person will develop Alzheimer’s disease (Alzheimer’s Association, 2008). This trend is expected to rise and it is predicted that 10 million baby boomers will develop Alzheimer’s disease at some point throughout their lifetime (Alzheimer’s Association, 2008). Family caregivers are often left responsible to care for their loved one as they progress throughout the course of the disease. There are currently 10 million Americans who care for a loved one with Alzheimer’s disease or another form of dementia (Alzheimer’s Association, 2008). Monitoring and maintaining the health of caregivers is important for the individual with Alzheimer’s disease because it allows the person with Alzheimer’s to remain in their familiar environment for as long as possible. It is estimated that approximately 70 percent of individuals diagnosed with dementia live outside of an institutional setting (Alzheimer’s Association, 2008). With these findings, it is evident that caregivers must be properly educated on how to maintain their personal health and well-being to adequately care for their loved one for extended periods of time.

Occupational therapists may assist caregivers in developing strategies that will allow them to maintain performance in important daily activities while incorporating the
demands associated with the caregiving role into their daily routine. Physical and emotional health of a caregiver may be negatively impacted with the demanding role of caregiving and occupational therapists can educate and assist caregivers in maintaining a balance between work, play, rest and sleep (O’Rourke, Cappeliez, & Neufeld, 2007; Watts & Teitelman, 2005). Occupational therapists are qualified to implement a variety of interventions directed towards improving and maintaining the health and well-being of caregivers. Occupational therapists have an understanding of how the relationship between a caregiver and care recipient can impact the health and well-being of both individuals and may assist in creating a healthy and positive environment (Hogan et al., 2003).

Research has concluded that a multicomponent approach has been most beneficial to caregivers when educating them on various topics relating to caring for an individual with Alzheimer’s disease (Sorensen, Pinquart, & Duberstein, 2002). This educational resource forum incorporates a multicomponent approach that is used to educate family caregivers of individuals with Alzheimer’s disease on how to cope and maintain personal health and well-being while adequately caring for their loved one. The development of this educational resource forum incorporates education, psychoeducation, support groups, and the identification of community resources to address various topics. These topics include the progression of Alzheimer’s disease, specific problematic behaviors to be expected and strategies that can be taken to promote safety and independence, ways caregivers can maintain and improve physical health through exercise and nutrition, proper coping strategies, and specific resources available in caregivers’ communities to decrease burden experienced. Activities and support groups
are implemented at the end of each session to facilitate a deeper understanding of the feelings and difficulties associated with the demands of caring for a loved one. This educational resource forum was intended for implementation by an occupational therapist, but with the use of this framework, it may be expanded to be used across disciplines including nursing, nutritionists, and psychologists.

Two different foundational approaches were utilized in the development of this educational resource forum. These include the Ecological Model of Occupation and, in general, the Adult Learning Theory. The following will explain the rationale of these two approaches and their relevance to the forum.

The Ecological Model of Occupation examines the relationship between four constructs that include person, context, task, and performance. Although all four constructs are equally important, this model emphasizes context because it may be overlooked in occupational therapy practice as well as by other healthcare professions (Dunn, Brown, & Youngstrom, 2003). This framework is unique in that it was intended to be used across disciplines to facilitate interdisciplinary collaboration (Dunn et al., 2003).

The Ecological Model of Occupation focuses on each person being unique and complex in terms of past experiences, values, interests, and skills which are called person variables (Dunn et al., 2003). These person variables can influence a person’s choice of task and the quality of their task performance (Dunn et al., 2003). Educators must be aware of the fact that these variables may greatly influence a caregiver’s attitude and willingness to accept the responsibility of caring for a loved one with Alzheimer’s disease.
Goals are accomplished through a large set of behaviors referred to as *tasks*. This term is familiar to individuals in other healthcare professions and is used in place of the occupational therapy term, occupations (Dunn et al., 2003). By using this terminology, there is an increase in interdisciplinary communication when using this framework. It is understood that *tasks* take on a different meaning for each individual and allow them to form specific roles that are important to them (Dunn et al., 2003).

Individuals engage in *tasks* within their *contexts*. The Ecological Model of Occupation describes *contexts* as “a set of interrelated conditions that surrounds a person” (Dunn et al., 2003, p. 226). Two kinds of *contexts* are emphasized within this framework and include temporal and environmental contexts. Temporal context includes chronological age, developmental stage, and life cycle (Dunn et al., 2003). Environmental context encompasses physical, social, and cultural aspects of the individual’s life (Dunn et al., 2003). Both these *contexts* can either facilitate or inhibit engagement in daily *tasks*. As a caregiver of an individual with Alzheimer’s disease, *context* can greatly impact participation and performance in meaningful *tasks* which is one reason it is important for healthcare providers to develop interventions to address this construct.

The final construct associated with the Ecological Model of Occupation is *performance*. *Performance* is defined as “both the process and the result of the *person* interacting with *context* to engage in *tasks*” (Dunn et al., 2003, p. 226). Individuals use past experiences and individual skills to determine *tasks* they want and need to do within a specific *context*. This educational resource forum allows caregivers to evaluate their *performance*, and the *performance* of their loved one, to develop strategies to improve level of functioning in all areas of daily *tasks*.
The Ecological Model of Occupation has four underlying assumptions. The first assumption is that "persons and their contexts are unique and dynamic" (Dunn et al., 2003, p. 233). Individuals are not able to understand a person without first understanding their context. The second assumption is that "contrived contexts are different from natural contexts" (Dunn et al., 2003, p. 235). Because performance may vary in a contrived context, assessment and intervention must be completed in the individual’s natural context. The third assumption associated with this framework is that "occupational therapy practice involves promoting self-determination and inclusion of persons with disabilities in all aspects of society" (Dunn et al., 2003, p. 236). Under this assumption, occupational therapists promote independence and increase participation in the person’s environment as much as possible. The final assumption is that "independence means meeting your wants and needs" (Dunn et al., 2003, p. 237). Occupational therapists focus on the individual’s goals using a client centered approach in all settings.

The Ecological Model of Occupation describes five intervention strategies that may guide practice. These five strategies include establish/restore, adapt/modify, alter, prevent, and create. These intervention strategies were incorporated throughout the development of this educational resource forum. For example, the adapt/modify approach was used when discussing environmental modifications that will assist caregivers in promoting safety and independence in the individual with Alzheimer’s disease within their natural environment. Other approaches were also incorporated throughout the development of the forum to meet individual needs of all caregivers.

The development of this educational resource forum for family caregivers of individuals with Alzheimer’s disease is congruent with the Ecological Model of
Occupation in many ways. This framework emphasizes context throughout, but stresses the importance of maintaining a balance between the person, task, context, and performance. Context is incorporated throughout the educational resource forum when discussing topics such as environmental modifications, problematic behaviors, and community-based resources. The importance of maintaining a balance between the person, task, and performance were indirectly addressed throughout the forum.

Many principles of Adult Learning Theory were incorporated into the development of this educational resource forum. These principles helped to guide the way that information was presented to caregivers throughout the forum to effectively meet individual needs of caregivers. The following further explains the major principles and practices of adult learning and how these principles were utilized in the development of this educational resource forum.

It is understood that adults have a vast array of knowledge from their many life experiences. It has been shown that adults learn best when these experiences are acknowledged and new information is incorporated into these past experiences and beliefs (Caffarella, 2002). This educational resource forum uses real life examples and scenarios to help further the understanding of new information by incorporating and building upon caregivers’ past experiences. In the support group discussions, information can be further individualized and affirmed.

It is understood that adults prefer to be actively involved throughout the learning process and prefer to learn information that is personally meaningful to them (Caffarella, 2002). Topics were chosen based on findings from the literature review that suggest difficulties frequently encountered by caregivers throughout the caregiving process. This
helps to ensure that the information chosen to be presented to caregivers is meaningful and can be applied in their current caregiving experience, starting with exploration within the support group context.

Adults have different ways of learning information (Caffarella, 2002). Throughout the development of this forum, individual learning style preferences were considered. To meet the individual needs of all caregivers, information was presented in a variety of ways including a visual PowerPoint® presentation, handouts, lecture, role playing, and discussion.

The following chapters are organized in a sequential order. Chapter II reviews pertinent literature findings and establishes a need for the educational resource forum. Chapter III describes the methodology employed in creating the product. The product is presented in its entirety in Chapter IV. A brief explanation of the approaches used in the development of each session is explained, suggested guidelines for implementation, objectives of the entire forum, advanced preparation, learning objectives for each individual session, and the contextual overview of each session are also given. The conclusion and recommendations for future implementation of the educational resource forum are included in Chapter V.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction

Because of the growing number of individuals diagnosed with Alzheimer’s disease, caregiver burden is a great concern for healthcare professionals. Loved ones, such as spouses and other family members, are often left responsible to provide assistance to these individuals which may lead to the disruption of many routines and can ultimately result in the decline of personal health and well-being. Monitoring and maintaining the health of caregivers is important for an individual with Alzheimer’s disease because it allows the individual to remain in their familiar environment for as long as possible. Healthcare professionals working with individuals who are diagnosed with the disease are responsible for assisting caregivers in maintaining their own health while caring for their loved one to ensure that they will not be placed in an assisted care facility prematurely. It has been proven that both physical and emotional health of a caregiver decline with the demands associated with caregiving. It is important to develop and implement interventions directed towards a caregiver of an individual with Alzheimer’s disease to promote overall health and well-being.

In order for caregivers of individuals with Alzheimer’s disease to function at their highest possible level, they must be educated on proper coping strategies to promote both emotional and physical health. Caregiver burden is defined as a negative experience resulting from increased stressors while caring for a loved one with a mental or physical
ailment (Faison, Faria, & Frank, 1999). Research completed by Steadman, Tremont, and Duncan Davis (2007) concluded that if individuals were satisfied with their relationship prior to their loved ones onset of dementia, caregivers had a lower level of perceived burden. Along with these findings, a prior satisfactory relationship also affected better communication and problem solving skills with an improved ability to adapt to problematic behaviors (Steadman et al., 2007). The following paragraphs discuss the research on burden and its effect on caregiver physical and emotional health.

Emotional Health of the Caregiver

Caring for a family member with Alzheimer’s disease may negatively affect one’s emotional health. In a study done by Wright, Hickey, Buckwalter, Hendrix, and Kelechi (1999), researchers found that there are higher rates of depression found in caregivers of individuals with Alzheimer’s disease. Depression is also found to be higher with caregivers of loved ones who tend to exhibit irritable behaviors, who previously had a decreased relationship satisfaction with the care recipient, and who experience personal health concerns (Mahoney, Regan, Katona, & Livingston, 2005). Depression, in turn, can contribute to a decrease in caregiver self-care, activities of daily living, motivation, and health enhancing behaviors, which ultimately may result in a decline in physical well-being (O’Rourke, Cappeliez, & Neufeld, 2007).

Anxiety is also found to be more prevalent in caregivers of individuals with Alzheimer’s disease (Mahoney et al., 2005). Consistent with caregiver depression, anxiety tends to be higher in female caregivers who live with the individual with Alzheimer’s disease, those who have a decreased relationship satisfaction with the care recipient, and who experience personal health concerns (Mahoney et al., 2005). It is
important for healthcare professionals to constantly monitor the emotional health of caregivers of individuals with Alzheimer’s disease because of the increased prevalence of depression and anxiety and its effects on the individual with Alzheimer’s disease level of functioning.

Behaviors such as aggression, paranoia, anger, apathy, and emotional instability from the individual with Alzheimer’s disease all were found to increase rates of caregiver stress (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Constant awareness of the care recipient’s activities and disposition while simultaneously managing household chores and daily tasks is a challenging and stressful responsibility for a caregiver. Research done by Lu and Wykle (2007) concluded that higher stress levels resulted in an increased level of psychological distress symptoms and a decrease in functional abilities.

Caregiver frustration and resentment towards the care recipient are also common possibilities. Caregivers may demonstrate anger and resentment towards the care recipient due to a decrease in social interaction and self-reflection increasing the likelihood of depression and anxiety (Croog, Burleson, Sudilovsky, & Baume, 2006). Researchers concluded that as many as 41% of spousal caregivers have occasionally had feelings of anger and resentment towards their loved one. Caregiver resentment or anger has been found to have a significant impact on caregiver and care receiver social interaction and emotional distress (Croog et al., 2006). These findings support the idea for the development of interventions that will assist caregivers in maintaining not only the health and well-being of their loved one, but also their personal health and well-being.
especially emotional health (Croog et al., 2006). This idea was further established by other researchers (Lu & Wykle, 2007; O’Rourke et al., 2007).

Along with these other emotional difficulties, grief is also expressed by caregivers of those with Alzheimer’s disease. Caregivers commonly grieve the loss of personal identity, loss of the relationship between the caregiver and the individual with the disease and other personal relationships, and a loss of privacy which all influence the ability to provide adequate care to their loved one (Sawatzky & Fowler-Kerry, 2003). In a study done by Sanders and Corley (2003), caregivers reported a loss of intimacy with their partner, role reversal, feelings of helplessness, and possibly even suicidal ideations. It has been found that spousal caregivers experience a greater loss of self when compared to adult children who are in the caregiving role (Skaff & Pearlin, 1992). Spousal caregivers experience less intimacy in their marital relationship and ultimately lose their sense of identity as a couple (Skaff & Pearlin, 1992). A decrease in caregiver and care receiver social participation is also included in the grieving process. In a study done by Hogan, Lisy, Savannah, Henry, Kuo, and Fisher (2003) researchers found that caregivers may limit participation in social events because of problematic behaviors displayed by the individual with Alzheimer’s disease (Hogan et al., 2003). All of these feelings negatively influence the caregiver’s health and ability to care for their loved one.

Financial strain can also add to the caregiver’s emotional burden and distract them away from the care recipient’s needs. The financial cost of treating Alzheimer’s disease and caring for an individual can be high. In a study conducted by Baanders and Heijmans (2007), results indicated that in households with only one income, financial strain was experienced to a greater extent. Depending on the employment status of the
individual with Alzheimer’s disease and their caregiver, financial strain may need to be considered.

Physical Health of the Caregiver

Along with the emotional stressors related to caring for an individual with Alzheimer’s disease, caregivers face the challenge of maintaining their physical health. While providing care, caregivers must constantly be vigilant of the care recipient’s actions to ensure safety throughout all hours of the day. Constant supervision can lead to an interruption in routines of the caregiver which can in turn lead to a disruption in sleep patterns, self-care activities, and a decline in cardiovascular health. It is recommended that caregivers be screened both physically and emotionally during the care recipient’s medical visits to address concerns and/or challenges the caregiver may be experiencing (Willette-Murphy, Todero, & Yeaworth, 2006). If the caregiver voices concern, proper interventions should be recommended by healthcare providers to ensure the physical health of the caregiver.

Sleep disturbances are also prevalent among caregivers of individuals diagnosed with Alzheimer’s disease which can lead to increased stress levels and decreased overall function in everyday activities. Researchers Willette-Murphy et al. (2006) studied 37 wife caregivers and found that on average they were receiving less than seven hours of sleep a night. They raised concern that individuals who get less than seven hours of sleep a night have a 30% higher mortality rate when compared to those who get more than seven hours of sleep a night. Sleep disturbances also contribute to the increased probability of anxiety, depression and decreased mood, and a sense of belonging (Willette-Murphy et al., 2006).
Caregiver Demographic Differences

*Gender*

The level of caregiver burden may vary according to a person’s gender, age, race, education, and income. Female caregivers report a higher level of burden associated with caring for a loved one with Alzheimer’s disease (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). Current literature on caregiver burden in general, all spoke of female caregivers experiencing a higher level of burden when compared to male caregivers. Female caregivers are more likely to view caring for a loved one with Alzheimer disease as an obligation as part of their role as nurturer (Gallicchio et al., 2002). As a result, female caregivers were found to spend more time with the care recipient and offer more assistance with daily activities, which may lead to an increase in tension and perceived level of burden (Gallicchio et al., 2002). Researchers Papastavrou et al. (2007) found that due to the traditional beliefs of a female’s role in the household, wives are often expected to take on the responsibility of the primary caregiver whereas husbands tend to seek out assistance from both family members and other informal healthcare providers. Husband caregivers are more apt to seek assistance from outside sources when faced with difficult caregiving duties because it is acceptable according to society’s traditional role expectations (Brown, Chen, Mitchell, & Province, 2007). Husband caregivers also are more willing to change their approach of caregiving when their wife has displayed changes in behaviors and physical health needs (Brown et al., 2007).

*Age*

Older caregivers of an individual with Alzheimer’s disease are more susceptible to physical health deterioration secondary to the added stress of caring for a loved one.
Researchers von Kanel et al. (2006) defined older caregivers as being 55 years of age or older with an average age of 72 years. Older caregivers of individuals with Alzheimer’s disease are at an increased risk of mortality and cardiovascular disease when compared to younger caregivers (von Kanel et al., 2006). Due to the stressful nature of caregiving, the natural aging process of a caregiver may be accelerated which may ultimately lead to the inability to adequately care for a loved (von Kanel et al., 2006).

Race

Ethnicity may also influence the manner in which the caregiver responds to care for their loved one. Haley et al. (2004) found that African American caregivers generally have a better attitude in regards to caregiving and report improved overall well-being when compared to Caucasian caregivers. African American caregivers also were able to find more benefits and rewards of caring for their loved one (Haley et al., 2004). Religion and cultural beliefs may explain why African Americans take great pride and report less psychological distress when in a caregiving role (Haley et al., 2004).

Premorbid Relationship Satisfaction

Along with a caregiver’s gender, age, and race, the relationship satisfaction with the care recipient prior to illness has shown to impact the perceived level of caregiver burden experienced. Caregivers who report a higher level of relationship satisfaction prior to a loved one’s diagnosis of Alzheimer’s disease indicate a lower level of burden when caring for them (Steadman et al., 2007). Caregivers who previously experienced a higher relationship satisfaction were better able to adapt to a loved one’s decline in mental and physical functioning as well as possible problematic behaviors (Steadman et al., 2007).
Education

A caregiver’s level of education may also considerably affect their ability to cope with the stressors involved with caring for a loved one with Alzheimer’s disease. Individuals with a higher level of education were better able to cope with the difficulties involved with caregiving because of previously learned skills required to successfully complete higher levels of education (Papastavrou et al., 2007).

All of these factors must be considered when assisting caregivers in maintaining their own independence and personal health. Healthcare professionals must be aware of the caregiver’s emotional health, physical health, and demographic information when evaluating the appropriate method of care.

Interventions for Caregivers

A number of interventions and approaches have been proven effective for caregivers of individuals with Alzheimer’s disease when assisting them to maintain their emotional and physical health. These interventions and approaches include caregiver education, psychoeducation, supportive therapy, respite services and/or adult daycare, psychotherapy, and a combination of above approaches.

Numerous benefits have been attributed to these interventions including a decrease in caregiver burden and depression and an increase in reported caregiver well-being (Sorensen, Pinquart, & Duberstein, 2002). Caregivers are provided with an opportunity to better understand the disease which leads to a better ability to care for their loved one (Sorensen et al., 2002). When familiar with the natural progression of Alzheimer’s disease, caregivers will be better prepared to effectively care for their loved one. When a caregiver is emotionally and physically stable, the individual with
Alzheimer's disease is better able to stay in their familiar environment for a longer period of time which may limit confusion and agitation (Mittelman, Haley, Clay, & Roth, 2006).

**Educational Intervention**

An educational approach provides caregivers of patients with Alzheimer's disease with information regarding the progression of the disease, possible problematic behaviors that may be exhibited by the patient, and skills that are necessary to adequately care for a loved one (Acton & Kang, 2001). Strategies that help minimize problematic behaviors are discussed so caregivers are prepared for the progression of the disease (Acton & Kang, 2001). Trained professionals provide caregivers with an opportunity to build skills that are needed to provide care and allow them to practice those skills in a safe environment with others who are in similar situations (Acton & Kang, 2001).

**Psychoeducational Intervention**

The psychoeducational approach differs from the educational approach in that it provides a structured environment with a trained leader providing information regarding the disease process along with the integration of supportive interventions that may be beneficial to the caregiver (Sorensen et al., 2002). Trained leaders prepare caregivers on how to appropriately respond to memory and behavioral problems that are commonly seen throughout the progression of Alzheimer's disease. Participants are able to share and discuss experiences related to caring for an individual with Alzheimer's disease (Acton & Kang, 2001). To best prepare caregivers, this approach should be used in conjunction with other approaches to ensure that caregivers obtain the necessary information needed to provide adequate care for their loved one (Sorensen et al., 2002).

**Supportive Therapy**
Another approach commonly used by caregivers of individuals with Alzheimer’s disease includes supportive therapy such as support groups. This approach provides caregivers with the opportunity to interact with other caregivers and share personal experiences and successes (Sorensen et al., 2002). Support groups are meant to promote interaction within a safe environment between individuals who are in similar situations (Sorensen et al., 2002). Caregivers should feel free to discuss concerns and share successful strategies used in coping with problematic behaviors and fears (Sorensen et al., 2002). Spiegel and Kimerling’s study (as cited in Drentea, Clay, Roth, & Mittelman, 2006) indicated that caregivers were able to discuss both positive and negative emotions commonly felt when caring for their loved one and are able to listen to how others have coped with the progression of the disease. Support groups have been incorporated into the lives of families who have been affected with illness or disease and have been proven to provide them with a temporary relief from the everyday stressors involved.

**Respite Services**

Respite care may also be an option that caregivers of individuals with Alzheimer’s disease may want to consider. Respite care is designed to provide periodic relief to caregivers with intermittent, short-term care for their loved one (Lewis, 2003). When respite care is used at appropriate times, it can be beneficial and provide relief from the burden associated with caregiving. Lawton, Brody, and Saperstein’s study (as cited in Mavall & Thorslund, 2007) found that seeking respite services from the onset of the disease has been more beneficial in maintaining the emotional health of the caregiver when compared to waiting until a crisis situation arises. These findings indicate that healthcare providers should be aware of these available services and inform caregivers to
assist in decreasing caregiver burden. Respite services have been proven to be more
effective in sustaining the caregiver’s emotional, physical, and mental health when used
in conjunction with other approaches (Mavall & Thorslund, 2007).

*Psychotherapy*

Another approach that has been proven to be effective with caregivers of
individuals with Alzheimer’s disease is psychological interventions including behavioral
therapy, cognitive therapy, and cognitive-behavioral therapy (Gallagher-Thompson &
Coon, 2007). Psychotherapy may be defined as an intervention that consists of the
identification of past experiences and how they influence a person’s current behavior
(Scheinholz, 2001). A trained professional assists caregivers in identifying negative
reactions that are provoked by problematic behaviors exhibited by the care recipient
(Acton & Kang, 2001). Once these negative reactions are identified, the therapist and
caregiver can then work together to identify appropriate strategies of how to handle the
situation in the future (Acton & Kang, 2001). In a study done by Gallagher-Thompson
and Coon (2007), researchers found that cognitive behavioral therapy proved to be
effective in decreasing depressive symptoms among caregivers. Psychotherapy differs
from the psychoeducational approach in that it focuses more on behaviors and thought
processes rather than increasing knowledge regarding the disease process (Acton & Kang,
2001).

*Multicomponent Intervention*

A multicomponent approach is the combination of education, psychoeducation,
supportive therapy, respite/adult day care, and psychotherapy. This approach has been
proven to be the most effective intervention used with caregivers because it focuses on a
variety of aspects related to caregiver burden (Sorensen et al., 2002). In a study done by Sorensen et al. (2002) researchers found that caregivers responded best when they were involved in both individual and group therapies. Individual interventions address issues related to caregiver well-being whereas group interventions focus more on maintaining functional performance by the care recipient (Sorensen et al., 2002). Interventions tend to be more effective when they include both cognitive and social components which focus on maintaining the psychological health of the caregiver (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). It is important for a caregiver to be informed of the different interventions available to them and explore the possibilities to find which ones would be most beneficial for their personal situation.

The Role of an Occupational Therapist

Occupational therapists are trained to assist caregivers in maintaining performance in daily occupations while incorporating the new role as a caregiver into their daily routine. To maintain physical and emotional health, and to adequately care for their loved one, caregivers must balance work, play, rest, and sleep on a daily basis (Watts & Teitelman, 2005). Occupational therapists are educated on how the relationship between the caregiver and the care recipient promotes well-being and can facilitate a healthy and positive caregiving experience (Hogan et al., 2003). Client centeredness guides occupational therapy practice allowing the therapist to individualize the intervention process to fit the particular needs of the caregiver and their loved one (Corcoran et al., 2002). The ultimate goal of an occupational therapist is to assist caregivers in maintaining their health and well-being which will in turn allow the
individual with Alzheimer's disease to remain in their familiar environment for as long as possible.

Occupational therapists are qualified to implement a variety of interventions directed towards improving and maintaining the health and well-being of caregivers. Interventions include caregiver training, environmental modifications, and community-based resources (Dooley & Hinojosa, 2004). The simultaneous implementation of these three interventions has been proven to be beneficial in increasing the well-being and decreasing the burden felt by the caregiver (Dooley & Hinojosa, 2004).

**Caregiver Approaches**

Caregivers often are unaware of typical behavioral problems and difficulties that they may face as their loved one progresses throughout the course of the disease. An occupational therapist can provide education and may recommend strategies that will facilitate performance in normal daily living tasks for both the caregiver and the individual with Alzheimer's disease (Dooley & Hinojosa, 2004). Some examples of these strategies may include developing a structured routine involving the individual with Alzheimer's disease that will keep them occupied throughout the day and provide them with a sense of accomplishment (Dooley & Hinojosa, 2004). Another strategy that occupational therapists have found to be successful with caregivers is the implementation of both auditory and visual cues to facilitate participation by the individual with Alzheimer's disease in familiar tasks. Examples of these strategies include breaking down activities, giving step by step directions, and eliminating unnecessary clutter to decrease confusion (Corcoran et al., 2002; Dooley & Hinojosa, 2004). The
implementation of these strategies may assist the individual with Alzheimer’s disease in successful participation in daily activities.

*Environmental Modifications*

Environmental modifications consist of adapting the physical environment of an individual with Alzheimer’s disease to promote safety and maintain the highest possible level of independence within their home environment (Dooley & Hinojosa, 2004). Behavioral problems including disorientation and forgetfulness require modification of the physical environment to ensure safety and promote independence of the individual with Alzheimer’s disease (Dooley & Hinojosa, 2004). Examples of environmental modifications include visual cues, monitors or alarms, and adaptive equipment to assist the individual in remaining safe and familiar with their surroundings (Corcoran et al., 2002; Dooley & Hinojosa, 2004). With a modified physical environment, an individual with Alzheimer’s disease may be less dependent on their caregiver which may account for decreased burden and an overall better caregiving experience.

*Community-Based Resources*

Occupational therapists provide caregivers with information regarding resources that are available within their community that will assist them in caring for their loved one with one Alzheimer’s disease. Support groups, meal delivery services, and adult day programs are examples of resources that are available that may assist in relieving burden often associated with caregiving (Dooley & Hinojosa, 2004). Performance in activities of daily living may also decline in individuals with Alzheimer’s disease. In a study done by Faison et al. (1999), researchers concluded that decreased ability to complete activities of daily living by the care recipient increases level of burden experienced by their caregiver.
Therefore, caregivers may benefit from community-based resources to assist their loved one in completing those tasks while providing the caregiver with a break from the responsibilities associated with caregiving. Caregivers may experience decreased anxiety and burden when utilizing outside resources because it provides them with a mental break from caregiving and allows them to focus on other issues not associated with caring for their loved one (McGrath, Mueller, Brown, Teitelman, & Watts, 2000).

When working with a caregiver of an individual with Alzheimer’s disease, occupational therapists must provide them with information regarding caregiver approaches, environmental modifications, and community-based resources. Occupational therapists encourage caregivers to participate in meaningful occupations that will assist them in preserving their own health (Hasselkus & Murray, 2007). The implementation of these three intervention strategies will assist the caregiver in maintaining their overall health and well-being as well as decrease the level of caregiver burden.

Summary

Current literature supports the importance of maintaining the health and well-being of a caregiver of an individual with Alzheimer’s disease. Emotional and physical health is negatively impacted with the increased demands associated with caregiving. Demographic differences including gender, age, race, premorbid relationship satisfaction, education, and income all are found to affect the experience felt by the caregiver. A variety of interventions have been proven to be beneficial to the caregiver population in decreasing burden and in improving overall health and well-being with multicomponent approaches being the most beneficial. Occupational therapists assist caregivers in developing strategies and identifying resources that may be used to promote successful
participation in daily activities with the individual with Alzheimer’s disease, which will in turn decrease burden felt by the caregiver. Due to the fact that there are a growing number of individuals diagnosed with Alzheimer’s disease, more resources and healthcare professionals need to be developed and available to caregivers in assisting them with the difficulties they may face as their loved one progresses throughout the course of the disease.

The next chapter will go further in depth regarding the need for an educational resource forum for caregivers of individuals with Alzheimer’s disease. It will explain the approach used in the development of this educational resource forum according to current literature. The process of locating literature relevant to the topic is described and the organization of information throughout is also further explained in Chapter III.
CHAPTER III
METHODOLOGY

The product described in the following chapter is an educational resource forum on how caregivers can maintain and improve overall health and well-being to adequately care for their loved one with Alzheimer’s disease. This forum is intended to provide occupational therapists and other healthcare providers who specialize in the area of dementia with educational resources that can aide in the implementation of a program specifically directed towards caregivers of individuals with Alzheimer’s disease. Caregivers can use the information provided to them in their everyday life and within their communities to decrease the level of burden that is often associated with caring for a loved one. During the session, caregivers will receive handouts on the information that will be presented and will be able to refer to the resources at any time in the future. The forum is designed to be a group learning experience comprised of six sessions, led by an occupational therapist, with a support group following each didactic lecture section.

The process of developing the educational resource forum began with a review of literature available on the topic. There currently is a multitude of research that supports the need for interventions directed towards maintaining the health and well-being of caregivers of individuals with Alzheimer’s disease. Several databases including PubMed, CINAHL, SCOPUS, and OT Search were utilized to locate literature relevant to the topic. Initially, scholarly articles that addressed common symptoms associated with caregiver
burden were selected. However, the literature search was later expanded to include articles that focused on specific approaches that have been utilized with caregivers of individuals with Alzheimer’s disease and demographic differences that contribute to increased burden felt by caregivers. A search of literature specifically related to occupational therapy was completed to identify the profession’s role in assisting caregivers in adequately caring for their loved one while stressing the importance of maintaining previous daily routines.

Selected articles were analyzed to interpret similarities and differences among the findings. The literature findings were then organized into an outline which served as the foundation for writing the literature review. During the process of analyzing the data and writing the literature review, important similar findings were identified and categorized. A majority of the authors stressed the importance of providing interventions for caregivers of individuals with Alzheimer’s disease. These findings suggested an emerging area of occupational therapy practice because of the increased number of individuals being diagnosed with Alzheimer’s disease and the demands that are placed on their family caregivers. Occupational therapists are educated on how the relationship between the caregiver and the care recipient promotes well-being and can facilitate a healthy and positive caregiving experience. The knowledge base of an occupational therapist will assist in the implementation and success of the forum. The forum was developed to be implemented in Grand Forks, North Dakota and surrounding areas but can be adapted to be used in other communities throughout the nation.

Following completion of the literature review, a theoretical model was chosen to assist in the development of the educational resource forum. The Ecological Model of
Occupation along with Adult Learning Theory were selected to guide the development of the forum. The Ecological Model of Occupation was chosen because of its emphasis on the four constructs of occupational performance: person, context, task, and performance. These four constructs must appropriately interact with each other on a daily basis for an individual to function at their highest possible level. When an individual becomes responsible for caring for a loved one with Alzheimer’s disease, these four constructs may become unbalanced which may lead to an inability to adequately care for themselves and others. Adult Learning Theory was also incorporated into the development of the forum to ensure that information was presented to caregivers in a way that met the individual learning needs and preferences of the caregivers.

After selecting the theoretical model, topics to be presented throughout the six sessions of the educational resource forum were selected based on the findings from the literature review. The topics incorporate foundational knowledge of the disease and educate caregivers on behaviors to be expected by their loved one. Caregivers will be provided with strategies that may be useful in limiting undesirable behaviors while optimizing functional performance and increasing safety of the individual with Alzheimer’s disease. The forum provides caregivers with coping strategies and techniques that may be used to maintain or increase physical and emotional health. Caregivers will also be introduced to resources they can access within their community that will assist in decreasing level of burden experienced.

After the topics of the forum were selected, the six sessions were developed using PowerPoint®. Pertinent information was included on each slide with additional information provided in the lecture notes. The presenter may use the information in the
lecture notes to further explain information presented on the each slide. Throughout the sessions, information will be provided using specific examples and real life experiences. Support groups are implemented at the end of each session which will allow caregivers to problem solve and learn from each other while discussing personal experiences related to caregiving.

Resources relating to each topic are included at the end of each PowerPoint® presentation to allow caregivers to access additional information when needed. The resources were organized based on the American Psychological Association (APA) format. The handout caregivers receive at the beginning of each presentation also include resources used in the development of the session.

The product is presented in its entirety in Chapter IV. Also included in Chapter IV is an explanation of the approaches used in development of the sessions, suggested guidelines for implementation, objectives of the entire forum, advanced preparation, learning objectives for individual sessions, and the contextual overview of each session.
There are currently 10 million Americans who care for a loved one with Alzheimer’s disease or another form of dementia (Alzheimer’s Association, 2008). This educational resource forum was designed to maintain or improve a caregiver’s physical and emotional health to enable them to adequately care for their loved one and allow the individual with Alzheimer’s disease to remain in their familiar environment for as long as possible. There currently are sessions available for caregivers of individuals with Alzheimer’s disease that address many topics using specific approaches. This forum however, incorporates an interdisciplinary, multicomponent approach using education, psychoeducation, support groups, and the identification of community resources to address these topics. An occupational therapy perspective has also been integrated throughout the forum to assist caregivers in recognizing the importance of incorporating familiar occupations into both their personal and loved ones daily routines. It is a series of six sessions that are designed to provide education and support to caregivers of individuals with Alzheimer’s disease. These sessions will be offered two times a week for three weeks. They will be facilitated within a two hour time frame with the first hour consisting of an informative approach and support group during the second hour that will be led by an occupational therapist. The facilitation of individual sessions will be lead by
a trained professional who has experience in working with individuals with Alzheimer’s disease as well as their caregivers. Professionals will be provided with the opportunity to contribute to their communities by donating their time to assist caregivers in developing skills needed to care for loved ones with Alzheimer’s disease. The following describes what each session will include.

Objectives of Forum

The focus of this forum is to provide caregivers of individuals with Alzheimer’s disease with education on the progression of the disease, provide strategies to successfully cope with problematic behaviors, and inform caregivers on ways to maintain or improve their personal physical and emotional health as well as their loved ones. All family caregivers will be invited to attend the forum regardless of the functional level of their loved one. The optimal outcome for caregivers is to decrease caregiver burden and increase their overall health and well-being. Healthcare providers will provide an evaluation form for caregivers to complete at the end of each session regarding the information that was presented. At the end of the six sessions, caregivers will be asked to provide feedback on the benefits and possible changes that could be made for future implementation of the forum.

This manual will provide healthcare professionals with information needed to successfully implement an educational forum directed towards caregivers. The following describes each session’s individual objective(s), a description of what the session entails, and provides healthcare professionals with the resources and suggested materials needed to implement the sessions.

Advanced Preparation
A room with the adequate space to seat approximately eight to ten people will be required to lead each session. A computer with PowerPoint®, a projector, as well as a projector screen will also be required. A printer and paper are necessary for the occupational therapist to provide handouts and resources for caregivers. The following describes each session's objectives and what it consists of.

Learning the Basics of Alzheimer’s Disease

Objectives

1. Participants will be able to define Alzheimer’s disease.
2. Participants will have the ability to identify signs and symptoms related to Alzheimer’s disease.
3. Participants will be informed on the stages and symptoms associated with Alzheimer’s disease.
4. Participants will be informed of the physiology and causes associated with Alzheimer’s disease.
5. Participants will become familiar with the importance of prevention in delaying the onset of Alzheimer’s disease.

Contextual Overview

Caregivers are often unfamiliar or confused with the progression of Alzheimer’s disease and the signs and symptoms often associated with it (Alzheimer’s Association, 2008). The purpose of this session is to assist caregivers in becoming educated on the disease so they are better able to successfully care for their loved one. A physician will introduce the topic with statistics related to Alzheimer’s disease that indicate the increased prevalence of the disease using a PowerPoint® presentation. The physician will define Alzheimer’s disease as the gradual loss of intellectual and social abilities that affect one’s daily performance and participation in activities (Mayo Clinic, 2008). Signs and symptoms will be presented and participants will be encouraged to ask questions and discuss concerns or experiences with the physician. The physician will explain the
progression of the disease in terms of the stages of Alzheimer’s disease so caregivers will have a better understanding of what to expect. The physician will review the known causes and physiology associated with Alzheimer’s disease. The use of a diagram will illustrate the physiological impact that Alzheimer’s disease has on the brain. Current trends in research will be described to caregivers to inform them of new developments and why prevention is important to delay the onset of Alzheimer’s disease. An occupational therapist will facilitate a support group at the end of the informative presentation to allow for caregivers to reflect on their loved one’s symptoms and their stage within the disease progression.

Learn to Expect the Unexpected

Objectives

1. Participants will be informed of common problematic behaviors exhibited in individuals with Alzheimer’s disease.
2. Participants will identify and rehearse strategies in coping with problematic behaviors.
3. Participants will discuss and learn from experiences of peers.

Contextual Overview

As the disease progresses, problematic behaviors often are exhibited by an individual with Alzheimer’s disease which may increase caregivers’ stress levels and decrease their ability to successfully care for their loved one (Alzheimer’s Association, 2008). The purpose of this session is to assist caregivers in identifying strategies that can be used to cope with problematic behaviors. This class will be led by an occupational therapist that will begin by informing caregivers of common problematic behaviors exhibited by individuals with Alzheimer’s disease. A PowerPoint® presentation will be used to describe these problematic behaviors and participants will be provided with the
opportunity to ask questions throughout the presentation. The occupational therapist will offer strategies on how to respond to problematic behaviors and caregivers will be able to role play a situation with their peers on how they will utilize these strategies. Caregivers will complete an occupational profile on their loved one to distinguish what areas of occupation are successful and what areas are difficult for their loved one. A support group will be implemented at the end of the presentation and caregivers will reflect on personal experiences with problematic behaviors and will practice using these strategies through role play.

Promoting Safety In and Around the Home

Objectives

1. Participants will become familiar with both mental and physical changes throughout the progression of Alzheimer’s disease that affect the individual’s safety.
2. Participants will be informed of environmental adaptations that can be made to promote safety within the home.

Contextual Overview

It is important for caregivers to maintain a safe environment to promote safety and to assist the individual in feeling relaxed and less overwhelmed (Alzheimer’s Association, 2007). The purpose of this session is to provide caregivers with information on specific adaptations that can be made within the individual’s home environment that will promote safety and increase participation in day to day tasks. An occupational therapist will introduce the session by informing participants on the mental and physical changes that influence safety in Alzheimer’s disease. A PowerPoint® presentation will be used to present information regarding environmental adaptations that can be made to promote safety within the home. The occupational therapist will introduce an activity that
initiates reflection on possible changes that can be made within the home of the individual with Alzheimer’s disease to make day to day tasks easier and safer. A support group will be incorporated at the end of the session so participants can further discuss possibilities that will assist them in caring for their loved one while ensuring safety.

How to Maintain Physical Health and Nutrition

Objectives

1. Participants will be informed of the benefits of physical exercise and proper nutrition.
2. Participants will be informed on nutrition guidelines according to the food pyramid.
3. Participants will be informed of ways to incorporate exercise and nutrition into their daily lives.

Contextual Overview

The demands associated with caregiving have been shown to decrease a caregiver’s physical and emotional health. Physical exercise and nutrition have been proven to decrease the rate of depression, reduce the risk of disease, and improve overall health (Center for Disease Control, 2007). The purpose of this session is to educate caregivers on how to maintain physical health through exercise and nutrition. An occupational therapist will provide caregivers with tips on how to incorporate exercise and proper nutrition into their daily routines. A PowerPoint® presentation will be used to present the information with an activity to follow consisting of a fruit and vegetable and exercise challenge. A support group will be incorporated at the end of the session to allow caregivers to reflect on their current lifestyle choices and discuss ways to live a healthier life which will ultimately increase their ability to adequately care for their loved one.

Coping with the Demands Associated with Caring for a Loved One
Objectives

1. Participants will become familiar with possible symptoms caused by increased stress levels.
2. Participants will be informed on factors that may increase stress levels and how to manage and prevent these symptoms.
3. Participants will be informed on strategies that may be used to manage anger and frustration.

Contextual Overview

It is common for caregivers of Alzheimer’s disease to demonstrate symptoms of increased stress, anger, and frustration. The purpose of this session is to educate caregivers on typical signs and symptoms associated with increased stress and anger related to caring for a loved one with Alzheimer’s disease. Caregivers will be informed of different strategies or techniques that may be implemented to deescalate a difficult situation and make for a more positive caregiving experience. An occupational therapist will present information using a PowerPoint® presentation. A coping activity and support group that facilitates discussion regarding current coping strategies and other possible coping strategies that may be employed in the future to further cope with the physical and emotional demands of caregiving.

Community-Based Resources

Objective

1. Participants will become familiar with local community resources that may assist them in maintaining their overall health and well-being while caring for their loved one.

Contextual Overview

Caregivers are often unfamiliar with resources available within their communities. The purpose of this session is to provide caregivers with information regarding possible services that may assist them in maintaining their own health and well-being while caring
for their loved one. A social worker will facilitate the session using a PowerPoint®
presentation to present caregivers with information. At the end of the session, an
occupational therapist will encourage participants to use the computer to research
resources within their communities that may be beneficial to them in the caregiving
process.

This PowerPoint® presentation has been completed and is specific to the Grand
Forks area and surrounding communities. Information will need to be adapted to the
appropriate location if utilized outside of this context.

Evaluation

Caregivers will be asked to complete an evaluation of the forum at the end of the
sixth session. The evaluation will ask caregivers to identify personal benefits and what
information could be added or adapted for future implementation of the forum. The
evaluation will consist of open ended questions so providers of the session will receive a
broader range of feedback to better improve their ability to care for their loved one and to
have a more positive caregiving experience. Please refer to Appendix A where you will
find the Forum Evaluation.

In the following pages of this product, you will find the PowerPoint® notes pages
for the six sessions of the educational resource forum. Within each session description,
more detail and resources are provided for the session speakers and participants. At the
end of each session, guiding questions for the support groups are provided.
LEARNING THE BASICS OF ALZHEIMER’S DISEASE
Session One
OBJECTIVES

- Participants will be able to define Alzheimer’s disease.
- Participants will have the ability to identify signs and symptoms related to Alzheimer’s disease.
- Participants will be informed of the stages and symptoms associated with Alzheimer’s disease.
- Participants will be informed of the physiology and causes associated with Alzheimer’s disease.
- Participants will become familiar with the importance of prevention in delaying the onset of Alzheimer’s disease.
• People today are living into their 80’s and 90’s due to advances in medicine and medical technology. The incidence and prevalence of Alzheimer’s disease results as people live longer and will continue to increase because the disease develops as people age.

• Alzheimer’s disease is the seventh leading cause of death for people of all ages and the fifth leading cause of death in people aged 65 and older.

• The highest death rate attributed to Alzheimer’s disease in 2003 was in North Dakota, where the rate was 53 out of 100,000 (336 deaths). The lowest death rate attributed to Alzheimer’s disease in 2003 was in Alaska, where the rate was 8.6 out of 100,000 (56 deaths).

• It is estimated that by mid-century, a person will develop Alzheimer’s every 33 seconds.
DEFINITION OF ALZHEIMER'S DISEASE

- A gradual loss of intellectual and social abilities that affect one's daily performance and participation in activities
- Most common form of dementia

### SIGNS AND SYMPTOMS

- Memory impairments
- Confusion
- Disorganized thinking
- Impaired judgment
- Difficulty with abstract thinking
- Trouble expressing themselves
- Difficulty with ADL’s

- Disorientation
- Difficulty performing familiar tasks
- Personality changes
- Decreased ability to communicate
- Inability to recognize familiar people

---

**It may start with slight memory loss and confusion, but will eventually lead to irreversible mental impairment that destroys a person’s ability to remember, reason, learn, and imagine.**

**Memory impairments**: It is normal to forget the names of people whom you rarely see, but it is not a normal part of aging to forget the names of familiar people and objects. People with Alzheimer’s disease may repeat things and forget conversations or appointments. They routinely misplace things, often putting them in illogical locations. They frequently forget names, and eventually, may forget the names of family members and everyday objects.

**Impaired judgment.** Solving everyday problems, such as knowing what to do if food on the stove is burning, becomes increasingly difficult, eventually impossible. Alzheimer’s disease is characterized by greater difficulty in doing things that require planning, decision making and judgment.

**Difficulty with abstract thinking**: People with Alzheimer’s disease may initially have trouble balancing their checkbook, a problem that progresses to trouble recognizing and dealing with numbers.

**Disorientation**: People with Alzheimer’s disease often lose their sense of time and dates, and may find themselves lost in familiar surroundings.

**Difficulty performing familiar tasks**: Once-routine tasks that require sequential steps, such as cooking, become a struggle as the disease progresses. Eventually, people with advanced Alzheimer’s disease may forget how to do even the most basic tasks.

**Personality changes**: People with Alzheimer’s disease may exhibit mood swings. They may express distrust in others, show increased stubbornness, and withdraw socially. As the disease progresses, people with Alzheimer’s disease may become anxious or aggressive and behave inappropriately.

**At the beginning stages of Alzheimer’s disease, symptoms progress slowly and may even be missed by the people who are closest to the individual.**

**The course of the disease varies from person to person. Eight years is the average length of time from the diagnosis of Alzheimer’s disease to death. Survival begins to decline three years after diagnosis, but some people may live more than a decade with the disease.**
STAGES OF ALZHEIMER'S DISEASE

- Stage One
  - Typically lasts 2-4 years
- Stage Two
  - Can last several years
  - Associated with "Sundowning"
- Stage Three
  - Typically lasts 1-2 years
  - Usually do not live at home at this point

STAGE ONE

- Memory loss
- Decreased spontaneity
- Personality change
- Disorientation


- The first stage is characterized by short term memory loss that is often difficult to differentiate from normal age-related forgetfulness.

- Individuals with Alzheimer's disease in stage one often forget where things are placed, get lost easily, have difficulty remembering appointments, and performing novel (new and unfamiliar) tasks.

- There may be mild changes in personality such as a lack of spontaneity, social withdrawal, and a loss of a previous sense of humor.
<table>
<thead>
<tr>
<th>STAGE TWO</th>
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<tbody>
<tr>
<td>o Impaired cognition</td>
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<tr>
<td>o Agitation</td>
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<tr>
<td>o Inability to carry out activities</td>
</tr>
<tr>
<td>o Impaired judgment</td>
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<tr>
<td>o Inappropriate social behavior</td>
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<tr>
<td>o Lack of insight</td>
</tr>
<tr>
<td>o Repetitive behavior</td>
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<tr>
<td>o Increased appetite</td>
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<tr>
<td>o &quot;Sundowning&quot;</td>
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- The second stage is also referred to as the confusional stage of dementia.
- This stage is marked by a more global impairment of cognitive functioning.
- Impaired cognition: There are changes in higher level functioning needed for language, spatial relationships, and problem solving.
- Inability to carry out activities and impaired judgment: There is extreme confusion, disorientation, lack of insight, and the inability to perform ADL's. Personal hygiene is neglected and language becomes impaired because of difficulty with word finding.
- Sundowning: Also known as sundown syndrome, usually occurs late in the afternoon or early evening. The individual may be confused, restless, agitated, become hostile towards caregivers, and begin to wander.
- Depression may become an issue at this stage of the disease.
- Individuals in this stage are often unable to live alone.
Stage Three

- Indifference to food
- Inability to communicate
- Urinary/fecal incontinence
- Seizures

- Stage three is a terminal stage and is relatively short when compared to the other stages.

- Individuals may become incontinent, apathetic, and unable to recognize family or friends.

- Most experts agree that Alzheimer's disease likely develops as a result of multiple factors rather than a single cause. The greatest risk factor is increased age.

- A small percentage of Alzheimer's disease is caused by rare genetic variations that may allow individuals as young as 30 years old to develop the disease. When this happens, it is commonly described as "early-onset" Alzheimer's disease.
- Healthy brains have billions of nerve cells called neurons which generate electrical and chemical signals that are relayed from neuron to neuron to help you think, remember, and feel. Chemicals called neurotransmitters help these signals flow seamlessly between neurons.

- Initially in people with Alzheimer's disease, neurons in certain locations of the brain begin to die and lower levels of neurotransmitters are produced, creating signaling problems in the brain.

- **Plaques**: It is believed that plaques are formed in the brain that are made up of a normally harmless protein called beta-amyloid that disrupts the communication between neurons leading to death of the neuron.

- **Tangles**: The internal support structure for brain neurons depends on the normal functioning of a protein called tau. In people with Alzheimer's disease, threads of tau protein undergo alterations that cause them to become twisted. Many researchers believe this may seriously damage neurons, causing them to die.

- **Inflammatory response**: Researchers have observed inflammation in the brains of some people with Alzheimer's disease. Inflammation is the body's response to injury or infection and a natural part of the healing process. Even as beta-amyloid plaques develop in the spaces between neurons, immune cells are at work getting rid of dead cells and other waste products in the brain. Although researchers believe the inflammation occurs before plaques have fully formed, they aren't sure how this development relates to the disease process. There is also debate about whether inflammation has a damaging effect on neurons or whether it is beneficial in clearing away plaques.
• Please refer to the source cited above for pictures of Alzheimer’s disease brain comparisons.

• The hallmark of Alzheimer’s disease is neuronal death occurring in regions of the cerebral cortex. If you compare the two, you will notice shrinkage of the folds and increased space between them.

• In the Alzheimer’s diseased brain, notice that the posterior aspect of the brain is not as atrophied as the other areas. Also notice the size difference of the temporal lobes in the Alzheimer’s brain versus the non-Alzheimer’s brain.
TREATMENT

- Medications
  - Used to delay memory loss and treat symptoms, but there is no known cure
  - Used to treat both cognitive and psychiatric symptoms
  - Currently five drugs are available to slow the progression of symptoms up to 6-12 months
- Referrals to other healthcare professionals as needed

There is no treatment available that can delay or stop the deterioration of brain cells in Alzheimer's disease.

The FDA has approved five drugs that may temporarily slow the worsening of symptoms for about 6-12 months for approximately half of the individuals who take them.

There are two categories of drugs that have proven to be effective in decreasing cognitive symptoms.

- The first being cholinesterase inhibitors which includes donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). They work by improving the levels of neurotransmitters in the brain. Donepezil has been approved by the Food and Drug Administration for the treatment of mild, moderate and severe Alzheimer's disease.

- Memantine (Namenda) is the first drug approved to treat moderate to severe stages of Alzheimer's. It protects brain cells from damage caused by the chemical messenger glutamate. It sometimes is used in combination with a cholinesterase inhibitor.

There are also drugs available that treat both behavioral and psychiatric symptoms. These medications are used to treat depression, anxiety, and psychotic symptoms.

Despite the fact that there is no cure for the disease, medications may be beneficial in improving quality of life.

Other healthcare professionals may include occupational therapy, physical therapy, case management, and speech therapy.
CURRENT RESEARCH

- Research indicates that prevention is “key” in avoiding or delaying onset of Alzheimer’s disease
  - Maintaining control of blood pressure, blood sugar, and cholesterol all help reduce risk


• Many scientists believe that evidence suggests that the health of the brain, one of the body's most highly vascular organs, is closely linked to the overall health of the heart and blood vessels. Management of cardiovascular risk factors such as cholesterol, blood sugar, blood pressure, and weight may assist in avoiding or delaying cognitive decline in the future.

• Evidence also suggests that regular physical exercise assists in maintaining lifelong cognitive health.

• There is also research supporting the idea that a robust social network, a lifetime of intellectual curiosity, and mental stimulation may also assist in maintaining cognitive abilities.
SUPPORT GROUP

- What signs and symptoms does your loved one currently display?
- What symptoms do you believe are the most difficult to deal with?
- What stage do you believe your loved one is in?
- What experiences, both positive and negative, do you have regarding medications?
RESOURCES


LEARN TO EXPECT THE UNEXPECTED

Session Two
Objectives

- Participants will be informed of common problematic behaviors exhibited in individuals with Alzheimer's disease.
- Participants will identify and rehearse strategies in coping with problematic behaviors.
- Participants will discuss and learn from experiences of peers.
<table>
<thead>
<tr>
<th>Common Problematic Behaviors</th>
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<tbody>
<tr>
<td>- Aggression</td>
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<tr>
<td>- Anxiety or Agitation</td>
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<tr>
<td>- Confusion</td>
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<tr>
<td>- Repetition</td>
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<td>- Suspicion</td>
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Aggression

- Verbal
  - Shouting or name calling
- Physical
  - Hitting and pushing
- May occur without reason or may be triggered from frustrating situations

• These behaviors may occur suddenly and without any apparent reason.

• Whatever the case, it is important to try understand what is causing the person to become angry or upset.
How do you Respond to Aggression?

- Try to identify the immediate cause
- Focus on feelings, not facts
- Don’t get angry or upset
- Limit distractions
- Engage in a relaxing activity
- Shift focus to another activity

• **Try to identify the immediate cause**: Ask yourself what happened right before the reaction that may have triggered the aggression.

• **Focus on feelings, not facts**: Look for the feelings behind the individual’s words. Do not focus on details, instead consider the emotions involved.

• **Don’t get angry or upset**: Speak in a soft gentle tone. Be positive and reassuring.

• **Limit distractions**: Consider the person’s environment and make changes to avoid similar situations.

• **Engage in a relaxing activity**: Incorporate activities that may relax the individual such as music, massage, or exercise.

• **Shift focus to another activity**: Redirect individual to a different activity because the initial activity at hand may have caused the negative response. Healthy behaviors are supported and maintained when individuals engage in occupations that are meaningful to them. When caregivers find activities that are meaningful to the individual, problematic behaviors may decrease.
Anxiety or Agitation

- Restlessness
- Pacing
- May become upset in certain situations or places
- Overly attentive to details
- Over reliant on certain people


- An individual with Alzheimer’s disease may feel anxious or agitated.
How do you Respond to Anxiety or Agitation?

- Listen to the frustration: Identify the cause of the anxiety and try to find ways to understand.

- Provide reassurance: Provide support by using calming phrases and let the individual know that you are there for them.

- Involve the person in activities: Try using art, music, or other activities to help relax the individual.

- Modify environment: Limit noise and distractions or relocate to a different room.

- Find outlets for the person’s energy: The individual may be bored. Try to involve them in activities such as going for a walk or working on a puzzle.
Confusion

- Difficulty recognizing familiar people, places, things
- Forgetting the purpose of common items

- Individual may forget relationships, confuse family members, or become confused about location of their home.

- The person may forget the purpose of common items such as a pen or fork.

- A lot of patience and understanding is required of caregivers whose loved ones are going through this stage of the disease because it can be extremely frustrating and difficult.
How do you Respond to Confusion?

- Stay calm
- Respond with a brief explanation
- Show photos or other reminders of past people and events
- Offer corrections as suggestions
- Try not to take it personally

formation/documents/brochures/behaviors.pdf

• Stay calm: Even though the situation may be difficult for the caregiver, do not express emotion in front of the individual with Alzheimer's disease.

• Respond with a brief explanation: Lengthy responses and reasons may be overwhelming to the individual. Keep explanations short and simple.

• Show photos or other reminders of past people and events: Use photographs and other thought-provoking items to remind the individual of important people and places.

• Offer corrections as suggestions: Avoid explanations that sound demeaning.

• Try not to take it personally: Remind yourself that you need to support your loved one. These symptoms are part of the progression of the disease and do not reflect back on you, as a caregiver, personally.
Repetition

- Repeating words, questions, or activities
- Pacing or "undoing"

Repetition, in most cases, means that the individual with Alzheimer’s disease is seeking comfort, security, and familiarity.

The individual may pace or undo activities that have just been finished. This behavior may be stressful, but caregivers should remind themselves that this behavior is not harmful to the individual.
How do you Respond to Repetition?

- Look for a reason behind the repetition: Identify the specific cause for the behavior.
- Focus on the emotion, not the behavior: Rather than reacting to the individual’s behavior, focus on the emotions behind the behavior.
- Turn action or behavior into an activity: Turn nonpurposeful activities into purposeful activities. For example, if the individual is repetitively rubbing their hand across a table, give them a cloth and ask for help dusting.
- Stay calm and be patient: Reassure the person with a calm voice and gentle touch.
- Provide an answer: Give the answer the individual is looking for even if you must repeat it several times.
- Engage the person in an activity: Provide structure and engage the individual in a meaningful activity.
- Use memory aids: Use reminders such as notes, clocks, calendars, and photographs if the person is continually asking the same questions over and over.
- Accept the behavior and work with it: As long as the behavior is not harmful to the individual, let it be. Find ways to work with the behaviors.
• Memory loss and confusion may cause individuals with Alzheimer's disease to interpret things in new and unusual ways.

• Individuals may become suspicious of those closest to them often accusing them of theft, infidelity, or other improper behavior.

• At times, an individual with Alzheimer's disease may misinterpret things they see or hear.
How do you Respond to Suspicion?

- Don't take offense: Listen to what is causing the individual to be upset and try to understand that it is reality to them. Be reassuring and demonstrate to the individual that you truly care.

- Don't argue or try to convince: Acknowledge the individual's expression of ideas and opinions.

- Offer a simple answer: Share your personal thoughts with the individual but do not overwhelm them with lengthy explanations or reasons.

- Switch focus to another activity: Engage the individual in a meaningful activity or ask for assistance with tasks around the house.

- Duplicate any lost items: If the individual is often searching for a specific item, have several of those items readily available. For example, if an individual is constantly looking for a specific pen, have many of the same pen available.

Occupational Profile

- An occupational profile describes an individual's occupational history and experience, patterns of daily living, interests, values, and needs.

- Designed to gain an understanding of the individual's perspective and background.

- Information is gathered to understand what is important and meaningful to the individual. It is also used to identify past experiences and interests that may assist in understanding current issues and problems.

- While gathering information, the individual's priorities and goals that facilitate engagement in occupation are also identified.

- Caregivers are required to reflect back on their loved one’s life and incorporate activities that were previously important to them into the individual’s daily life activities.

Occupational Profile

- Ask yourself the following questions regarding your loved one:
  - What are the strengths and weaknesses of your loved one?
  - What are the individual's concerns about their ability to perform daily routines?
  - What activities are successful for the individual and what activities are causing difficulty?
  - What parts of the physical environment promote and inhibit performance in daily activities?
  - What are the individual's life experiences, values, interests, and activities previously participated in?
    - What is the meaning associated with each of these?
  - What are the individual's priorities and goals?

Support Group

- Discuss personal experiences and ask yourself the following questions.
- Behaviors:
  - What is the behavior?
  - Is it harmful to the individual or others?
  - Is it triggered by certain events?
  - What is your reaction to this behavior?
  - Is this behavior caused by side effects of medications?
• **Responses:** Caregivers will demonstrate both appropriate and non-appropriate reactions to experiences through role play.
Resources


OBJECTIVES

- Participants will become familiar with both mental and physical changes throughout the progression of Alzheimer's disease that affect the individual's safety.
- Participants will be informed of environmental adaptations that can be made to promote safety within the home.
• Caregivers of individuals with Alzheimer’s disease need to take specific precautions to create a safe environment for their loved one. These precautions should allow them to function at the highest possible level.

• **Judgment**: An individual may forget how to use common household objects.

• **Sense of time and place**: Individuals may lose their sense of direction and have difficulty recognizing or finding familiar locations.

• **Behavior**: Individuals may become easily confused, suspicious, or fearful.

• **Physical ability**: Individuals may experience decreased balance and may require a walker or wheelchair for mobility.

• **Senses**: Individuals may experience decreased vision, hearing, temperature sensitivity, and depth perception.

• It is important to promote safety at all times because it can prevent injuries and assist in helping the individual to feel more relaxed and less overwhelmed. A caregiver must constantly be aware of possible safety hazards within the individuals environment to assist in meeting their needs.
It is important to keep these documents accessible at all times in case of an emergency.

Keep this information in an easily accessible location within the home and take them with you when you are away for an extended period of time.

Also, keep a second copy of this information in a location away from the home.
FOCUS ON PREVENTION

- Try not to expect the individual to automatically do things safely
- Eliminate hazardous materials
- Be patient and slow down
- Make activities simple
- Balance safety with needs for privacy and independence
- Be realistic


- Safe environments can assist in preventing injuries, so caregivers should assess the environments of individuals with Alzheimer’s disease for potential hazards.

- Try to relate to what the individual is going through. Adapt the environment to the needs of the individual.

- **Be patient and slow down:** Accidents can happen when a person is rushed.

- **Make activities simple:** Simplify routines and provide step-by-step directions, especially during complex personal care activities such as bathing, toileting, and dressing.

- **Be realistic:** There is no way that a caregiver can anticipate every risk and prevent every problem.
**EVALUATE THE ENVIRONMENT**

<table>
<thead>
<tr>
<th>Locations:</th>
<th>Prevention:</th>
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<tbody>
<tr>
<td>Garage</td>
<td>Fire extinguishers</td>
</tr>
<tr>
<td>Work rooms</td>
<td>Smoke alarms</td>
</tr>
<tr>
<td>Basement</td>
<td>Carbon monoxide detectors</td>
</tr>
<tr>
<td>Outside areas</td>
<td>Secure sharp utensils and electric appliances</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Avoid falls by use of grab bars, etc.</td>
</tr>
<tr>
<td>Bathroom</td>
<td></td>
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</tbody>
</table>

*These rooms may be equipped with dangerous equipment, uneven surfaces, and other hazards that may compromise safety.*

*Be sure to test prevention equipment on a regular basis to ensure that it is functioning properly.*
• Due to changes in the brain, individuals may not understand that swallowing foreign objects could cause choking or poisoning.

• **Lock up all medications**: Keep vitamins, medication, sugar substitutes, and seasonings off the counter to avoid confusion. Also, keep track of how many pills are being taken.

• **Be prepared for the unusual**: Some individuals with Alzheimer's disease may eat items such as gravel or dirt.
Inability to correctly use common items
Be aware that safe devices have the potential to be hazardous
Place appliances at eye level
Supervise the individual while in the kitchen
Safe proof the kitchen area
Monitor electric cords
Place safety covers on electric outlets
Use appliances that have an auto shut-off feature and keep appliances away from water sources

• **Inability to correctly use common items:** Individuals may not remember how to use appliances and tools. Potential hazards may include toaster ovens, stoves, coffee makers, power tools, lawn mowers, and barbeque grills.

• **Be aware that safe devices have the potential to be hazardous:** For example, an individual may try to open a can by jabbing at it with a screwdriver.

• **Safe proof the kitchen area:** Lock up knives, hide appliances, remove knobs from stoves, unplug all heat producing appliances, and consider turning off gas and electricity from specific areas.

• **Monitor electric cords:** Do not allow cords to dangle and regularly check for frays, breaks, or other damage.

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Keep in mind that individuals with Alzheimer’s disease may lose sensitivity to temperature extremes and may forget about the dangers of extreme temperatures.

**Be cautious of heat producing items:** Such items include stoves, space heaters, curling irons, microwave prepared foods, electric blankets, and heating pads.

**Be aware of temperature of water and food:** Set the hot water heater to 110 degrees Fahrenheit and install anti-scald devices on faucets.

**Avoid accidents associated with cooking and eating:** Turn pan handles to middle of stove top, don’t wear loose clothing while cooking, do not place containers with hot liquid near the edges of countertop, pour hot liquids away from the individual’s body, test the temperature of microwave foods, and use placemats instead of tablecloths.
**PREVENTING SLIPS AND FALLS**

- Non-skid shoes
- Reduce clutter
- Place sturdy items that can be leaned upon in hallways or frequently traveled paths
- Limit the rearrangement of furniture
- Maintain flooring properly
- Wipe up all spills immediately
- Keep stairways safe


- **Reduce clutter:** Remove throw rugs, extension cords, and other obstacles. Do not let pets sleep in traffic areas.

- **Keep stairways safe:** Keep stairways well lit, provide handrails on both sides, ensure that steps are even and uniformly deep, and use a contrasting color along the edges of steps.
BATHROOM SAFETY

- Grab bars
- Bath benches
- Commode chairs
- Non-slip mats
- Remove electrical appliances
- Install ground fault outlets near all water sources

• Individuals with Alzheimer's disease often have difficulty distinguishing between colors and have difficulty understanding what they see because of changes in their vision.

• **Even level lighting**: Changes in level of light can be disorienting. Add extra light in entryways, outside areas, hallways, bedrooms, and bathrooms.

• **Night lights**: Place night lights in hallways, bedrooms, and bathrooms to increase safety.
Keep all firearms in a safe, locked cabinet, firearm vault, or storage case
- Keep firearms unloaded
- Store ammunition in a secure place away from firearms
- Supervise and be in complete control of firearms at all times
- Seek assistance from public officials if unsure of proper handling or disposal of weapons
- Discard firearms completely

If you choose to keep these items in the home, take great precautions because operating firearms requires sound judgment with alert senses.
• Individuals with Alzheimer’s disease are at risk for wandering and becoming lost. More than 60% of individuals with dementia will wander and if not found within 24 hours, the individual may suffer from serious injury or death.
**Things to Consider When Wandering Becomes a Problem**

- Identify times of the day that wandering may most likely occur
- Engage the individual in daily household tasks
- Limit fluids
- Monitor reactions to medications
- Try to distract the individual when they begin to wander


- **Identify times of the day that wandering may most likely occur:** Plan activities during that time of the day to assist in preventing wandering.

- **Limit Fluids:** When night wandering becomes a problem, limit fluids two hours before bedtime and make sure the individual has gone to the bathroom before bed. Also, try to limit daytime naps.
TIPS TO REDUCE WANDERING

- Use deadbolts and place them either high or low on exterior doors.
- Promote exercise to decrease anxiety, agitation, and restlessness.
- Ensure all basic needs are met.
  - Ex: toileting, hunger.
- Engage individual in household activities.
- Reassure individual if they feel lost, abandoned, or disoriented.
- Control access to car keys.
- Avoid busy places that are confusing.
- Do not leave individual unsupervised in unfamiliar places.

TIPS TO REDUCE WANDERING

- Night lights
- Cover door knobs with cloth that is a similar color to the door
- Use childproof knobs
- Paint doors the same color as walls
- Cover doors with screens or curtains
- Place warning bells above doorways
- Use pressure-sensitive mats at doorways or bedside to alert when there is movement

TIPS TO REDUCE WANDERING

- Construct a fence or hedge around yard or patio
- Use safety gates or bars across stairways
- Reduce noise levels to decrease confusion
- Label all doors and explain the purpose of each room
- Secure items that suggest leaving
  - Ex: coat, keys, wallet

There are programs available nationwide designed to assist caregivers in limiting wandering and locating the individuals who have become lost.

**Develop a list of individuals to call when feeling overwhelmed:** Keep telephone numbers in an easily accessible location.

**Keep a recent photo of the individual:** Have an easily accessible photo to provide to officials in an emergency.

**Become familiar with your neighborhood:** Identify dangerous areas within your neighborhood such as bodies of water, open stairwells, dense foliage, tunnels, bus stops, and roads with heavy traffic.

**Consider hand dominance:** Typically, individuals tend to wander in the direction of their dominant hand.

**Keep a list of previously familiar places to the individual:** Develop a list of places the individual would likely wander to such as previous job locations, former homes, churches, or restaurants.
• The demands of driving require adequate judgment, quick reaction time and decision making. Unfortunately, with the progression of the disease, individuals will eventually be unable to drive.

• It can often be difficult to convince the individual that it is time to stop driving. To assist in this process, caregivers may seek out the help of professionals to administer a driving evaluation. The following may assist in the process of removing driving privileges:

  • Encourage law enforcement to issue a citation.
  • Ask the individual's doctor to write a “do not drive” prescription.
  • Control access to car keys.
  • Disable the vehicle by removing the distributor cap or battery.
  • Remove the vehicle from the individual's line of sight.
  • Encourage the individual to be tested by the Department of Motor Vehicles.

• It is important for caregivers to learn about other modes of transportation before restricting all driving privileges. Schedule transportation from other family members, friends, or community services.
Reflect on individual's current environment.
- Identify both positive and unsafe environmental features within the individual's home.
- Identify specific objects and locations that can be adapted to promote safety.
- Identify other strategies that will be effective.
Are there any adaptations that you as the caregiver have already implemented?
  - Was the adaptation helpful?
What adaptations do you plan on making within the individual's home after being informed of these safety tips?
  - How do you plan on administering these adaptations?
Have you found and implemented other adaptations that were not mentioned in this presentation?
  - In what ways were they beneficial to the individual with Alzheimer's disease?
RESOURCES


How to Maintain Physical Health and Nutrition
Session Four
Objectives

- Participants will be informed on the benefits of physical exercise and proper nutrition.
- Participants will be informed on nutrition guidelines according to the food pyramid.
- Participants will be informed of ways to incorporate exercise and nutrition into their daily lives.
Facts on Caregiver Physical Health

• One in ten caregivers report that caregiving has worsened their physical health
• Caregivers suffer from increased physical ailments including acid reflux, headaches, and aches and pains
• Caregivers have an increased risk of developing serious illnesses and have higher levels of obesity

• Caregivers have increased blood pressure and insulin levels, impaired immune systems, and are at an increased risk for cardiovascular disease.

• Studies have also found that caregivers who experience caregiving related stress have a 63% higher mortality rate when compared to non-caregivers of the same age.

• Studies have also shown that approximately one third of caregivers provide exhausting care even though they themselves are in fair to poor physical health.
Benefits of Physical Exercise and Proper Nutrition

• Reduces the effects of depression and anxiety
• Reduces the risk of stroke, coronary heart disease, Type II diabetes, colon cancer
• Lowers cholesterol, triglycerides, and blood pressure
• Assists in achieving and maintaining healthy body weight
• Assists in building healthy bones, joints, and muscle
• Assists in maintaining mobility and endurance

• Reduces the effects of depression and anxiety: Physical exercise has been shown to reduce or alleviate symptoms of depression. It is unknown if physical activity prevents the onset of depression or helps modify the effect. Regardless, physical exercise is beneficial in coping with depression.
How to Incorporate Exercise into Daily Life?

- Establish a walking routine and partner
- Schedule specific times of the day to exercise
- Join exercise classes
- Take the stairs rather than elevator or escalator
- Park vehicle further away
- Take walk breaks instead of coffee breaks
- Perform gardening or home repair activities
- Exercise while watching TV
- Dance to music


Food Pyramid

- Grains
- Vegetables
- Fruits
- Milk
- Meat and Beans
- Oils

Grains

- Any food made from wheat, rice, oats, cornmeal, barley, or other cereal grain products
  - Examples include bread, pasta, oatmeal, breakfast cereals, tortillas, and grits
  - At least half of the grains consumed should be whole grains
  - It is recommended to consume 5-6 ounce equivalents per day


- One ounce equivalent is equal to one slice of bread, one cup of ready to eat cereal, and one half cup of cooked rice or pasta.

- Tips:
  - Substitute whole grain products for a refined product. For example, switch from white to wheat bread.
  - Eat brown rice or whole wheat pasta.
  - Add whole grain flower or oatmeal to cookies or other baked treats.
  - Popcorn is a healthy snack with little or no salt or butter.
Vegetables

- Vegetables may be raw, cooked, crushed, frozen, fresh, canned, dried, whole, cut up, or mashed
- It is recommended to consume 2-2 ½ cups per day


- One cup of raw or cooked vegetables or vegetable juice or two cups of raw, leafy greens can be considered one cup from the vegetable group.

- Tips:
  - Buy fresh vegetables in season. They cost less and are likely to be at their peak flavor.
  - Stock up on frozen vegetables for quick and easy cooking in the microwave.
  - Buy vegetables that are easy to prepare. Pick up pre-washed bags of salad greens and add baby carrots or grape tomatoes for a salad in minutes. Buy packages of veggies such as baby carrots or celery sticks for quick snacks.
  - Use a microwave to quickly “zap” vegetables. White or sweet potatoes can be baked quickly this way.
  - Vary your veggie choices to keep meals interesting.
  - Try crunchy vegetables. Raw or lightly steamed.
Fruits

- Fruits may be fresh, canned, frozen, dried, whole, cut up, or pureed
- It is recommended to consume 1 ½ - 2 cups per day

One cup of fruit or 100% fruit juice, or a half cup of dried fruit can be considered one cup from the fruit group.

Tips:
- Keep a bowl of whole fruit on the table, counter, or in the refrigerator.
- Refrigerate cut-up fruit for later.
- Buy fresh fruits in season when they may be less expensive and at their peak flavor.
- Buy fruits that are dried, frozen, and canned as well as fresh fruits, so that you always have a supply on hand.
- Consider convenience when shopping. Buy pre-cut packages of fruit for a healthy snack in seconds. Choose packaged fruits that do not have added sugars.
Milk

- All fluid milk products and many foods made from milk are considered part of this food group
- Most milk group choices should be fat-free or low-fat
- It is recommended to consume three cups per day

Foods made from milk that retain their calcium are part of the group, while foods made from milk that have little to no calcium (cream cheese, cream, butter) are not.

One cup of milk or yogurt, one and a half ounces of natural cheese, or two ounces of process cheese equal one cup.

Tips:
- Include milk as a beverage at meals. Choose fat-free or low-fat milk.
- If you drink cappuccinos or lattes, ask for them with fat-free milk.
- Have fat-free or low-fat yogurt as a snack.
- Make fruit or vegetable dip from yogurt.
- Make fruit-yogurt smoothies in a blender.
- For dessert, make chocolate or butterscotch pudding with fat-free or low-fat milk.
- Top cut-up fruit with flavored yogurt for a quick dessert.
- Top casseroles, soups, stews, or vegetables with shredded low-fat cheese.
- Top a baked potato with fat-free or low-fat yogurt.
Meats and Beans

- All foods made from meat, poultry, fish, dry beans or peas, eggs, nuts, and seeds are considered part of this group.
- It is recommended to consume 5-5 ½ ounce equivalents per day.

• One ounce of meat, poultry, or fish, one fourth cup of cooked, dry beans, one egg, one tablespoon of peanut butter, half ounce of nuts or seeds can be considered a one ounce equivalent.

• Tips:
  - Purchase lean beef cuts such as round steaks and roasts. Consider any meat with the name “loin” in it.
  - Purchase extra lean ground beef.
  - Use skinless chicken parts.
  - Trim away all visible fat from meats and poultry.
  - Broil, grill, roast, poach, or boil meat, poultry, or fish instead of frying.
Oils

- Fats that are liquid at room temperature
  - Examples include corn oil, canola oil, olive oil, soybean oil, sunflower oil
- It is recommended to consume 5-6 teaspoons per day

Most Americans consume enough oil in the foods they eat such as nuts, fish, cooking oil, and salad dressings.

The fat that is found in fish, nuts, and vegetable oils do not raise LDL or “bad” cholesterol levels in the blood. In addition to the essential fatty acids they contain, oils are the major source of vitamin E in typical American diets.
**Activity**
- Fruit and Vegetable Challenge
- Exercise Challenge

- **Fruit and Vegetable Challenge:** This challenge will assist caregivers in increasing their amounts of fruits and vegetable intake to improve overall health.

  - Please record the number of fruits and vegetables you ate at each meal for four weeks. Makes copies of the tracking form to continue to monitor intake of fruits and vegetables in future months.

  - The challenge is to eat five fruits and five vegetables a day.

- **Exercise Challenge:** The exercise challenge will assist caregivers in tracking amount of daily exercise.

  - The challenge is to exercise between 12 - 15 times this month, which is at least three times each week. Make copies of the tracking form to continue to monitor amount of physical activity in future months.

  - Exercise and nutrition is necessary to be healthy both physically and emotionally. It is important to develop ways to incorporate these practices into daily life activities.
Support Group

- Do you currently feel you get enough exercise?
- Do you feel that you eat a well balanced diet?
- What barriers are inhibiting a healthy lifestyle?
- How can you overcome those barriers?
- How can you incorporate a healthy lifestyle into your daily routine?
- Have you ever felt that you physically were unable to complete tasks associated with caregiving?
- Can you think of any ways to incorporate a healthier lifestyle for both you and your loved one?
Resources


Coping with the Demands Associated with Caring for a Loved One

Session Five
Objectives

- Participants will become familiar with possible symptoms caused by increased stress levels.
- Participants will be informed on factors that may increase stress levels and how to manage and prevent these symptoms.
- Participants will be informed on strategies that may be used to manage anger and frustration.
<table>
<thead>
<tr>
<th>Symptoms Associated with Caregiver Stress</th>
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<tbody>
<tr>
<td>• Denial</td>
</tr>
<tr>
<td>• Anger</td>
</tr>
<tr>
<td>• Social withdrawal</td>
</tr>
<tr>
<td>• Anxiety</td>
</tr>
<tr>
<td>• Depression</td>
</tr>
<tr>
<td>• Exhaustion</td>
</tr>
<tr>
<td>• Sleeplessness</td>
</tr>
<tr>
<td>• Irritability</td>
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<tr>
<td>• Lack of concentration</td>
</tr>
<tr>
<td>• Health problems</td>
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</tbody>
</table>

- If you experience these signs of stress on a regular basis, it is probably time to see your doctor.

- **Denial**: Denial about the disease and its effect on the individual who has been diagnosed.

- **Anger**: Anger at the individual with Alzheimer’s disease or others, that there is no cure that exists, and that people don’t understand what is going on.

- **Social withdrawal**: Social withdrawal from friends and activities that once brought pleasure.

- **Anxiety**: Anxiety about facing another day and what the future holds.

- **Depression**: Depression that begins to break your spirit and affects your ability to cope.

- **Exhaustion**: Exhaustion that makes it nearly impossible to complete necessary daily tasks.

- **Sleeplessness**: Sleeplessness caused by an never ending list of concerns.

- **Irritability**: Irritability that leads to moodiness and triggers negative responses and actions.

- **Lack of concentration**: Lack of concentration that makes it difficult to perform familiar tasks.

- **Health problems**: Health problems that begin to take their toll both physically and emotionally.
Factors Influencing Stress Levels

- Voluntary caregiving
- Premorbid relationship
- Coping abilities
- Caregiving situation
- Available support

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it.

**Voluntary caregiving:** If caregivers have a choice in taking on responsibilities they may experience less strain, distress, and resentment.

**Premorbid relationship:** Some caregivers feel that by caring for their loved one, past discrepancies within their relationship will be healed.

**Coping abilities:** How a caregiver has coped in the past will influence how the caregiver will cope with stresses associated with caregiving. Identify current ways of coping that have been successful in your life and build on them.

**Caregiving situation:** Some caregiving situations are more stressful than others. For example, it is sometimes more difficult to care for someone who has a cognitive impairment versus someone who has a physical impairment.

**Available support:** It is important to remember that you are not in this alone!
Steps to Manage Stress

- Recognize warning signs early
- Identify sources of stress
- Identify what you can and cannot change
- Take action

• **Recognize warning signs early**: Know your personal warning signs. Examples may be irritability, sleep problems, and forgetfulness. Make changes right away, so don't wait until you are overwhelmed.

• **Identify sources of stress**: Ask yourself “What is causing stress for me?”. Examples may be too many things to do, family disagreements, feelings of inadequacy, and the inability to say “no”.

• **Identify what you can and cannot change**: Remember that you can only change your actions, no one else’s. When you try to change things that are out of your control, you will only increase your frustration level. Ask yourself “What do I have some control over?” and “What can I change?”.

• **Take action**: Taking action to reduce stress can provide you with a sense of control. Simple activities such as walking, gardening, meditation, or having coffee with friends all can decrease stress levels.
Ways to Prevent Stress

- **Understand the disease**: Become educated on the symptoms associated with Alzheimer's disease. Understand behaviors and possible personality changes that may occur throughout the process.

- **Identify community resources**: Identify places within your community that provides information or assistance regarding Alzheimer’s disease care.

- **Take care of yourself**: Eat a proper diet and get enough physical exercise and rest to ensure that you remain healthy.

- **Accept changes as they occur**: The needs of your loved one will change and as a caregiver, you will be required to adapt to those changes.

- **Make legal and financial plans**: Plan ahead regarding legal and financial issues. Involve the individual with Alzheimer’s disease and other family members whenever possible.

- **Give yourself credit**: Know that the care you provide makes a difference and that you are doing the best you can. You may feel guilty because you can’t do more, but individual care needs change as Alzheimer’s disease progresses. You can’t promise how care will be delivered, but you are ensuring that the person with Alzheimer’s is well cared for and safe.
Anger

- An emotional state that varies in intensity from mild irritation to intense fury and rage

• Like other emotions, anger is often accompanied by physiological and biological changes. When you get angry your heart rate and blood pressure go up, as well as the levels of your energy hormones, adrenaline, and noradrenaline.

• Anger can be caused by both external and internal events. You could be angry at a specific person or event, or your anger could be caused by worrying about personal problems.
Anger Management

- The goal of anger management is to reduce both your emotional feelings and the physiological arousal that anger causes.

Anger is a completely normal and is usually a healthy, human emotion. When it gets out of control and turns destructive, it can lead to problems at work, in personal relationships, and in the overall quality of life.

- You can't get rid of or avoid the things or the people that enrage you, nor can you change them, but you can learn to control your reactions.
Strategies to Control Anger

- Relaxation
- Cognitive Restructuring
- Problem Solving
- Better Communication
- Using Humor
- Changing your Environment

Some simple steps you can try:

• Breathe deeply, from your diaphragm; breathing from your chest won't relax you. Picture your breath coming up from your "gut."

• Slowly repeat a calm word or phrase such as "relax" or "take it easy". Repeat it to yourself while breathing deeply.

• Use imagery. Visualize a relaxing experience from either your memory or your imagination.

• Nonstrenuous, slow yoga-like exercises can relax your muscles and make you feel much calmer.

• Practice these techniques daily. Learn to use them automatically when you're in a tense situation.
Cognitive Restructuring
- Changing the way you think

Angry people tend to curse, swear, or speak in highly colorful terms that reflect their inner thoughts. When you're angry, your thinking can get very exaggerated and overly dramatic. Try replacing these thoughts with more rational ones. For example, instead of telling yourself, "Oh, it's awful, it's terrible, everything's ruined," tell yourself, "It's frustrating, and it's understandable that I'm upset about it, but it's not the end of the world and getting angry is not going to fix it anyhow."

Be careful of words like "never" or "always" when talking about yourself or someone else.

Remind yourself that getting angry is not going to fix anything and probably won't make you feel better. It may actually make you feel worse.
Problem Solving

- Make a plan and check your progress along the way

- Focus on giving it your best. Do not punish yourself if an answer doesn't come right away.

- The best attitude to bring to a situation is not to focus on finding the solution, but on how to handle and face the problem.

- If you can approach the situation with your best intentions and efforts and make a serious attempt to face it directly, you will be less likely to lose patience and fall into all-or-nothing thinking, even if the problem does not get solved right away.
Better Communication

- Slow down and think through your responses

Angry people tend to jump to and act on conclusions. Some of those conclusions can be very inaccurate. The first thing to do if you're in a difficult situation is slow down and think through your responses. Don't say the first thing that comes into your head, but slow down and think carefully about what you want to say. Try to listen carefully to what the other person is saying and take your time before answering.

Listen to what is underlying the anger.

It's natural to get defensive when you're criticized, but don't fight back. Listen to what is underlying the words or the message that the person is portraying. For example, the individual might feel neglected and unloved. It may take a lot of patience on your part and may require some breathing space, but don't let your anger let a discussion spin out of control. Keeping your cool can keep the situation from becoming a disastrous one.
Using Humor

• “Silly humor” can help defuse rage
• Assists in getting a more balanced perspective
• Assists in deescalating intense situations

There are two cautions in using humor.

• Don't try to "laugh off" your problems. Instead use humor to help yourself face them more constructively.

• Don't give in to harsh, sarcastic humor. It is just another form of unhealthy anger expression.
Changing your Environment

- Sometimes it is our immediate surroundings that give us cause for irritation and fury

- Give yourself a break. Make sure you have some "personal time" scheduled throughout the days that you know are going to be particularly stressful.
Activity

- Pat is caring for his wife, Betty, who is in stage three of Alzheimer's disease. She is becoming increasingly intrusive and difficult to redirect. As a caregiver, Pat is becoming frustrated and angry. He begins to swear at Betty and repeatedly asks why she cannot change her behavior. Is there a more effective way for Pat to handle the situation?

• The occupational therapist will present caregivers with four different case scenarios that represent a negative caregiving situation.

• Case scenarios will be distributed to each caregiver and they will be asked to role play positive reactions to the situation for the rest of the group.

• The occupational therapist will facilitate a group discussion by asking caregivers if they have previously experienced a similar situation. Further discussion will include their reaction to the situation and whether or not they received a positive or negative response from the individual with Alzheimer's disease.
Activity

- Family and friends have noticed that Betty's ability to drive has been decreasing. They have mentioned to Pat that she may need a driving evaluation. Pat makes excuses for Betty and continuously puts off scheduling a driving evaluation. What symptom is Pat currently experiencing related to caregiving stress? How can awareness be increased in this situation in regards to Betty's difficulties and how they impact her safety and that of others?
Activity

- Betty now requires help with all self-care activities and is beginning to wander throughout the day and night. Pat feels worn out and does not feel that he is able to take care of himself or other household tasks because of a lack of sleep. How can Pat improve his quality of sleep to ensure that he remains healthy and adequately be able to care for Betty?
Activity

- Pat tends to be consumed with his role as a caregiver. His friends and family have noticed that he is no longer attending activities that he used to enjoy such as church and his neighborhood bridge club. Pat misses his friends and the socialization that takes place at these activities. How can Pat incorporate these meaningful activities into his daily routine while continuing to adequately care for Betty?
Support Group

- Describe a time you may have felt that you had to prove that you are worthy of the care recipient's affection?
- Describe a time that you felt you were being selfish when you put your needs first?
- Is it frightening to think of your own needs?
  - What is the fear about?
- Why might you feel inadequate if and when you ask for assistance in caring for your loved one?

Support Group

• How do you adjust or cope when you feel like you have no control or that things are unfair?
• Do you currently feel like you have control over your life?
  • In what ways do you feel you could gain more control?
• Identify some stress reducers that personally work for you.
  • In what ways do you find them beneficial?
Resources


Objective

- Participants will become familiar with local community resources that may assist them in maintaining their overall health and well-being while caring for their loved one.
Respite Care

- Respite care is designed to provide periodic relief to caregivers with intermittent, short-term care for their loved one (Lewis, 2003).
- **Altru Home Services**
  - Cheryl Rayer
  - Home Health and Hospice Manager
  - (701) 780-5880
  - (800) 545-5615

- There are numerous respite services available within the Grand Forks community. The one listed is provided through the local hospital.
### Nursing Homes

- **Valley Memorial Homes**
  - **Hearthstone**
    - A specialized care unit for individuals diagnosed with Dementia
    - Grand Forks, ND
    - (701) 787-7900

- **Riverview Care Center**
  - Nursing home consisting of a specialized Alzheimer’s unit
    - Crookston, MN
    - (218) 281-9465
Counseling Services

- **Altru Social Services**
  - (701) 780-5345
  - Monday – Friday 8:00 AM to 4:30 PM
- **Northeast Human Service Center**
  - (701) 795-3000

- **Altru Social Services:**
  - Members of the Altru Social Services Department are professionally trained to assess a patient’s and families holistic needs and are committed to providing comprehensive services to both patients and their families.
  - Altru Social Services is available to patient’s and their families free of charge.
  - Your physician or nurse may refer you or you can request to see a social worker.

- **Northeast Human Service Center:**
  - Services may be directed towards adults and the aging population.
  - Programs and services are available to help older adults and people with physical disabilities to live safely and productively in the least restrictive and appropriate setting.
Meals on Wheels

- Provides home delivered meal services to individuals in need
- Meals on Wheels in your Community:
  - Greater Grand Forks Senior Center
    - (701) 772-7245
  - Red River Valley Community Action
    - (701) 746-5431
    - (800) 450-1823

- Often times caregivers feel overwhelmed by the duties associated with caring for their loved one.

- Registering for this service may reduce stress because it is one less duty to worry about.
• Merry Maids individualizes cleaning services to you and your home. The price is based on many factors including the size of your home and the frequency of cleaning.

• Again, registering for this service may reduce stress levels because it is one less duty to worry about.
24/7 Helpline

- Provides reliable information and support to those who need assistance
- Contact Information for 24/7 Helpline:
  - (800) 272-3900

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- Highly trained and knowledgeable staff can assist you with:
  
  - Understanding memory loss, dementia, and Alzheimer's
  
  - Medications and other treatment options
  
  - General information about aging and brain health
  
  - Skills to provide quality care and to find the best care from professionals
  
  - Legal, financial, and living-arrangement decisions

- The 24/7 Helpline can also assist caregivers with confidential care consultation by master's level clinicians who can aide in decision making, crisis assistance, and education. Clinicians may provide the caregiver with referrals to local community programs, services, and other support networks.
MedicAlert & Safe Return

- Program provided through the Alzheimer's Association:
  - Provides assistance when an individual with Alzheimer's disease wanders off
  - Access to vital medical information in a time of need

How the program works:

- When an individual with dementia wanders or becomes lost, the caregiver may immediately call to activate a community support network that will help reunite the lost individual with their caregiver.

- When the individual is found, a citizen or law official calls the toll-free 24-hour emergency response number on the identification product (bracelet or pendant) and the individual's family or caregivers are contacted.

- The nearest Alzheimer's Association office provides support during search and rescue efforts. In addition, should medical attention be required, access to a personal health record is immediately available.

Enrollment Package:

- MedicAlert Identification bracelet or pendant
- Wallet card
- "6 Steps to a Safe Return" magnet
- Personal Health Record Summary
- Alzheimer's Association brochure
Transportation

- Grand Forks City – Cities Area Transit (CAT), Senior Rider
  • (701) 787-9120
Support Groups

- Alzheimer’s Caregiver/Family Support Groups:
  o First Saturday of the month
  o 10:00 a.m.
  o UND College of Nursing, Third Floor
  o University Avenue and Harvard Street
  o Liz Tyree (701) 777-4522

- Alzheimer’s Caregiver/Family Support Groups:
  o Last Monday of the month
  o 6:00 to 7:30 p.m.
  o Parkwood Place Meeting Room
  o 749 30th Street
  o Brent Gillund (701) 772-6618
Alzheimer's Association of North Dakota

- Eastern Chapter
  - Grand Forks, ND
  - (701) 746-4669
• Caregivers will be asked access the internet and identify resources they would find beneficial within their community.
Support Group

- What kind of community resources have you utilized within your community?
- Which resources did you find to be the most beneficial and why?
- Are there any other community resources that you would like more information on?
- How do you plan to utilize these community resources?
  - Do you plan to seek out these community services independently or with others?
Resources


CHAPTER V
SUMMARY

The product presented in the preceding chapter is an educational forum that will assist family caregivers of individuals with Alzheimer’s disease. It consists of PowerPoint® slides, lecture notes, and handouts that caregivers may use at a later date. Support groups guided by an occupational therapist are provided at the end of each of the six forum sessions. The forum is intended to assist caregivers with the difficulties that they may face when caring for a loved one who has been diagnosed with Alzheimer’s disease.

The educational resource forum is designed to be implemented within the Grand Forks, North Dakota community. However, this forum may be adapted to fit the needs of other demographic areas nationwide. It may be used in a variety of settings including hospitals, wellness centers, senior citizen centers, nursing homes, and other healthcare facilities that provide services to individuals with Alzheimer’s disease and their family caregivers. There currently are opportunities within the Grand Forks community for implementation of this educational resource forum because there are limited resources available for caregivers in individuals with Alzheimer’s disease in this area. Due to the fact that there are a significant number of individuals diagnosed with Alzheimer’s disease, there will continue to be an increased need for occupational therapists to provide services and resources to caregivers to promote overall wellness and decrease potential feelings of burden felt by the caregiver.
It is recommended that this educational resource forum take on a more interdisciplinary approach and incorporate other healthcare providers from a variety of disciplines during implementation including a nurse, psychologist, and nutritionist. In doing so, different perspectives will be shared on how to maintain the health and overall well-being of family caregivers of individuals with Alzheimer’s disease.

It is also recommended that the facilitator of the forum will adapt the sessions according to feedback that caregivers provide at the previous session’s evaluation (See Appendix A for the Forum Evaluation). This will ensure that all caregiver needs are being met and all topics of interest are being addressed adequately throughout the implementation of the forum.

In the future, this educational resource forum could be expanded to include caregivers of individuals with various types of dementia diagnoses. Possibilities for the future include educating caregivers other than family members on how to adequately care for an individual with dementia and other related disorders. By including all caregivers, a larger population of caregivers will be reached contributing to the success of the forum.

There currently is a vast array of literature addressing the topic of caregivers of individuals with Alzheimer’s disease. Due to this fact, information had to be condensed to address all areas of importance for caregivers. The topics of this forum could be expanded upon to go further in depth when discussing areas of concern suggested by current literature. Possible topics for future expansion include sessions specifically addressing stress management and relaxation techniques.

The product created here provides caregivers with information to maintain their physical and emotional health while caring for their loved one with Alzheimer’s disease.
The information provided in the forum is intended to be adapted and/or expanded upon according to future literature findings and feedback provided from caregivers in the forum evaluation.

This scholarly project includes the need for the forum as established by the findings of a literature review, the identification of a theoretical approach that was used throughout, the methodology that was used in development of the product, and recommendations for future implementation of this educational resource forum. In summary, further opportunities for healthcare providers are expected due to the increased prevalence of Alzheimer's disease and the resulting demands that are placed on the caregivers who care for them.
APPENDICES
APPENDIX A
Forum Evaluation

1. What information did you find to be beneficial?

2. What information do you think could be eliminated?

3. Were there any topics that you would like to be addressed in the session/forum that were not?

4. What did you like about the way the information was presented?

5. How do you feel information could have been presented better?

6. Would you recommend this forum to other caregivers?

Additional comments:
APPENDIX B
Fruit and Vegetable Challenge

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*Please record the number of fruits and vegetables you ate at each meal!!
*The challenge is to eat 5 fruits and 5 vegetables each day!!!*
APPENDIX C
Exercise Challenge

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*The challenge is to exercise between 12 - 15 times this month, which is at least three times each week!!!*
REFERENCES


Corcoran, M.A., Gitlin, L.N., Levy, L., Eckhardt, S., Vause Earland, T., Shaw, G. et al. (2002). An occupational therapy home-based intervention to address dementia-
related problems identified by family caregivers. *Alzheimer’s Care Quarterly*, 3(1), 82-90.


