

Copyright
by
Andrea Michelle Mog

**The Report Committee for Andrea Michelle Mog
Certifies that this is the approved version of the following report:**

A Guide for Caregivers of Adults with Dementia

**APPROVED BY
SUPERVISING COMMITTEE:**

Supervisor:

Maya L. Henry

Thomas P. Marquardt

A Guide for Caregivers of Adults with Dementia

by

Andrea Michelle Mog, B.S. C.S.D.

Report

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Master of Arts

The University of Texas at Austin

May 2015

Dedication

In loving memory of Ross Allen Maxwell. I miss you, buddy.

Acknowledgements

I would like to thank my amazing parents, Michael Mog and Annette Ramos, for all that they have done for me. I would not be the person I am today without their guidance and support and am truly blessed to be their daughter. I would also like to thank all of my professors and clinical advisors, who I hope to emulate in my future career. I would especially like to thank Maya Henry and Thomas Marquardt for supervising this report.

Abstract

A Guide for Caregivers of Adults with Dementia

Andrea Michelle Mog, M.A.

The University of Texas at Austin, 2015

Supervisor: Maya L. Henry

As the aging population grows, so will the number of families who will face the challenge of caring for a loved one with dementia. This can be incredibly difficult and frustrating for caregivers who have no prior knowledge of dementia or formal training in how to cope with it. This report is meant to serve as an introductory guide to caring for a person with dementia. The sections are intended to be useable as stand-alone handouts that may be shared with family members and caregivers. They include brief summaries of the condition, common interventions, and common complications. Additionally it provides information about healthcare workers and facilities that can provide services to both the patient and the family.

TABLE OF CONTENTS

Introduction.....	1
What is Dementia?	3
What Are Signs of Dementia?	4
Stages of Dementia	6
Early Stages	6
Middle Stages.....	7
Late Stages	7
Management of Dementia	8
Getting a Diagnosis	8
Who Can Help?	8
What can be done to Help?.....	10
Pharmacological Interventions	10
Memory and Cognition Interventions.....	11
Other.....	13
What Are Feeding Complications?.....	16
Feeding	16
Dysphagia	17
Aspiration Pneumonia	17
Dysphagia Management.....	18
Tube Feeding.....	19
What Kind of Assistance is Available?	20
Adult Daycare	20
In-Home Health and Respite Care Services.....	21
Assisted Living Facilities	21
Skilled Nursing Facilities.....	22
How Can I Take Care of Myself?.....	23
Conclusion	25
References	27

INTRODUCTION

Dementia is a degenerative neurological condition that is prevalent in older adults. It is responsible for a range of symptoms that gradually worsen over time. Dementia presents with cognitive decline, behavioral changes, and a loss of ability to function independently (Tzeng & Eisendrath, 2002). Although the most widely-recognized cognitive symptom of dementia is memory loss, many other cognitive impairments may occur, such as changes in personality, impaired judgment, and even loss of language. Unfortunately, many of these early symptoms are overlooked and wrongfully assumed to be the result of normal aging. As such, diagnosis and treatment are often not sought until dementia has progressed to mid or late stages. In the later stages of dementia, many adults lose their ability to live independently and must rely on loved ones and caretakers to meet their daily needs. It is often overwhelming and difficult for loved ones to take on the care of an adult with dementia, especially those who have limited knowledge of the disease.

Approximately 14% of adults in the United States that are 71 years and older have some form of dementia. Although this statistic may seem low, it means that there are 3.4 million people affected by the disorder (Plassman et al., 2007). Additionally, due to an increase in life expectancy and the aging baby boomer generation, the elderly population is expected to double between the years 2011 and 2030 (Federal Interagency Forum on Aging-Related Statistics, 2005). This means that the number of individuals with dementia is expected to rise as well as the number of caregivers and families who will need to learn to cope with the disease. Caregivers often do not have adequate knowledge of the disease and can find it difficult not only to care for their loved ones, but to take care of themselves as well (Gruffydd, & Randle, 2006). The purpose of this paper is to

educate caregivers regarding dementia and its complications, to give resources for treatments and interventions, and to serve as an overall guide for what to expect when caring for someone who has the disorder.

WHAT IS DEMENTIA?

The Diagnostic and Statistical Manual of Mental Disorders-V (DSM-V) (American Psychiatric Association, 2013) lists dementia under an umbrella term of neurocognitive disorders, as it has many causes. To be diagnosed with a neurocognitive disorder, an individual must demonstrate the following:

- A decline in at least one cognitive domain, such as:
 - Attention: A person may have difficulty focusing on specific tasks such as listening, reading, or cooking.
 - Executive Function: A person may have difficulty initiating and executing behaviors to get goals and/or basic needs met.
 - Learning and memory: A person may have difficulty retaining new information.
 - Language: A person may have difficulty expressing themselves appropriately or have difficulty with reading and writing.
- A decline in cognition that results in the loss of total independence
- These cognitive deficits are not the result of other mental disorders

Because dementia is progressive, many of the earlier signs and symptoms are overlooked until the disease has progressed into later stages. Early symptoms of dementia are often mistaken for absentmindedness or “normal aging” (Boyd, 2013). For example, many adults misplace common everyday objects such as keys, but a person with dementia, on the other hand, may leave their keys in odd places such as the microwave. Occurrences such as this may be easy to overlook, or even laugh off, but are often early, subtle signs of the disorder.

What Are Signs of Dementia?

As we age, our bodies, including our brains, change. Changes in the brain can be compared to changes in joints or muscles. A person may still be able to do the things they once did when they were younger, but tasks may take longer to complete or may be more difficult to accomplish. In a study that compared performance on cognitive tasks such as spatial orientation, inductive reasoning, arithmetic, and word fluency, Schaie (1989) found that the only difference in performance between older and younger adults was the time it took for older adults to complete tasks. In other words, healthy older adults are no less intelligent than young adults, but may need more time to complete cognitive tasks. Because there is a misconception that aging automatically means a decline in cognitive function, early signs of dementia are often overlooked and considered to be part of the normal aging process (Knopman, 1998). This is problematic, as early detection and intervention can help both the patient and the family in preparing for and coping with the disorder. Early diagnosis allows for education of family and caregivers, who may not otherwise understand and become frustrated with the changes occurring in their loved ones (Leifer, 2009).

There are many different types of dementia, but the most common is Alzheimer's dementia (AD). AD accounts for 60-80% of cases of dementia (Barnes & Yafe, 2011) and is more prevalent in women than in men (Brookshire, 2007). AD is considered a cortical dementia, meaning that there are changes in the gray matter, or cortex, of the brain, which causes symptoms such as deficits in memory. Other types of dementia include subcortical dementias, which result from diseases such as Huntington's disease and Parkinson's disease, and often manifest in conjunction with motoric changes; and mixed dementias, which are caused by both cortical and subcortical changes. Many types

of dementia are referred to as proteinopathies, meaning that abnormal buildup of proteins within and around brain cells causes those cells to die. However, dementia can also be caused by vascular changes in the brain, akin to mini strokes that ultimately result in disabling cognitive changes. The five most common dementias are as follows (Types of Dementia, 2015):

1. Alzheimer's disease (AD): This is the most common form of dementia. It is most likely to occur after age of 65. AD is caused by plaques and neurofibrillary tangles in the brain, which result in cognitive and behavioral disturbances.
2. Vascular dementia: This is the second most common form of dementia. It occurs when the vascular system cannot get adequate blood to the brain, resulting in the death of brain tissue (infarct).
3. Lewy body dementia: Lewy bodies are abnormal buildups of protein that sometimes occur in the brain. When they occur in the cortex they can cause memory loss as well as other cognitive deficits.
4. Parkinson's disease: Parkinson's disease is caused by the formation of Lewy bodies in a deep brain structure called the substantia nigra. These Lewy bodies interfere with the production of dopamine, a neurotransmitter important for executing smooth movement. Parkinson's disease may also present with cognitive changes consistent with dementia.
5. Frontotemporal dementia (FTD): This type of dementia typically occurs in adults under the age of 65. It is caused by cell damage in the frontal and/or temporal lobes of the brain, resulting in speech, language or behavioral disturbances.

Early signs of dementia can appear long before the disease begins to take an obvious toll on daily life. These subtle signs include exhibiting changes in personality,

becoming less engaged in activities that were once enjoyed, and having mood swings (Brookshire, 2007). Another telling sign of dementia is increased difficulty learning and retaining new information (Hyman, Van Hoesen, Damasio, & Barnes. 1984). Due to the nature of dementia, patients typically are not able to recognize a decline in function and it often becomes the responsibility of family members to accurately relay information to a doctor (Knopman, 1998). Family members should become concerned when they notice that a loved one is beginning to lose their independence. Some patients will begin to lose their sense of orientation and awareness, their ability to recognize familiar places, and their capacity to complete functional tasks such as paying bills or managing medications. Although depression often accompanies dementia (Boland, 2000), it can also cause cognitive deficits similar to those of dementia (in non-demented individuals), such as personality changes and apathy (lack of interest). For this reason, it is important that physicians be made aware of any observed changes, not only in cognition, but also in mood or behavior.

Stages of Dementia

Although stages of dementia will look different across the various types, an overview of the stages of AD will be provided to give a general idea of the progression of dementia (Bourgeois, & Hickey, 2009).

EARLY STAGES

As discussed earlier, symptoms in the early stages of dementia are easily overlooked. In the mild stages of dementia, individuals may have difficulty with word-finding and comprehension of abstract language. They may begin to exhibit mild memory deficits and have difficulty completing complex tasks, such as balancing a checkbook. At

this stage, patients are typically aware of their deficits, and may use strategies, such as talking around a word, to compensate.

MIDDLE STAGES

As dementia progresses, patients will likely have increased difficulty with language. Word-finding deficits may increase while topic maintenance in conversational speech becomes more challenging. Patients may also begin to have difficulty understanding complex ideas or tasks. Reading comprehension often begins to decline during this stage. Behavioral disturbances may become more apparent, as patients begin to lack inhibition, have increasing difficulty with attention, and have worsening memory deficits.

LATE STAGES

In the later stages of dementia, language may become repetitive and inappropriate. Some individuals become mute. Attention and memory are severely impaired, and auditory comprehension may become very limited.

MANAGEMENT OF DEMENTIA

Getting a Diagnosis

A critical role for family members and loved ones is to recognize the signs of dementia and accurately relay that information to a physician, as dementia is a medical diagnosis that is made by a doctor. It may be easier to discuss these signs when the patient is not present, as the subject of dementia may engender feelings of fear or hostility (Knopman, 1998). Family members may ask their physician to administer examinations such as *The Mini-Mental State Examination (MMSE)* (Folstein, Folstein, & McHugh, 1975) or *The Short Test of Mental Status (STMS)* (Kokmen, Naessens, & Offord, 1987). Both are quick screening measures that determine if the examinee has a cognitive impairment, thus necessitating further testing. The *MMSE* tests a person's awareness/orientation, ability to follow simple commands, reading, writing, memory, and visuospatial abilities. *The Short Test of Mental Status* is similar to the *MMSE* but focuses more on abstract reasoning. If it is determined that the patient does have a cognitive impairment, further testing can be done to determine whether or not that impairment is, in fact, dementia. Not all cognitive impairments are associated with a diagnosis of dementia. These measures can help a physician determine whether or not further testing is warranted.

Who Can Help?

Because many family members and caregivers are unfamiliar with the disorder and may feel overwhelmed trying to manage troubling behaviors, it is important that they learn about dementia and are aware of what resources are available to them. There are many healthcare professionals who can work with the patient and their caregivers to

target and manage troublesome behaviors. The following list outlines the range of professionals who commonly play a role in treating individuals with dementia.

- Primary Care Physician—diagnoses and provides medical treatment for individual with dementia. Oversees medical care and refers to other specialized healthcare professionals.
- Geriatrician—a doctor who specializes in health and medical care for older adults. Can manage and develop treatment plan for an individual with dementia.
- Physical Therapist (PT)—works with patients to improve mobility, reduce pain, and perform activities of daily living (ADLs). PT's teach patients to safely move using devices such as walkers and wheelchairs while monitoring and managing safety issues such as falling.
- Occupational Therapist (OT)—works with patient and caregivers to determine a patient's ability to perform ADLs (such as feeding, dressing, toileting, etc.) and identifies troublesome behaviors and strategies to cope with them. OTs may recommend environmental changes, provide training, and find ways to simplify daily tasks.
- Speech-Language Pathologist—provide cognitive and communication therapy as well as evaluate and provide therapy for swallowing disorders. Speech-language pathologists can educate the family and provide strategies, such as the use of memory books, to remedy communication breakdowns.
- Social Worker—provide support and case management for patients and family members. Can provide needed resources, such as support groups, manage discharge plans with care providers, and counsel staff members of rehabilitation and nursing facilities.

What can be done to Help?

It is important to monitor the person with dementia to determine their level of independence. Activities such as cooking, paying bills, managing medication, and driving may no longer be safe or possible for people with dementia. If diagnosed during the earlier stages, the patient can be involved with planning for the progression of the disease (Knopman, 1998). It is important for family members to remember that coping strategies will have to change as the disease progresses. Below are some management approaches that can be used in the mild to moderate stages of dementia.

PHARMACOLOGICAL INTERVENTIONS

Unfortunately, there is currently no cure for dementia or way to reverse any damage that has already been caused at the neural level. The two leading pharmacological interventions, cholinesterase inhibitors and memantine, are meant to delay the progression of dementia and provide some relief of the symptoms associated with it (medications for memory loss).

- **Cholinesterase inhibitors:** Cholinesterase inhibitors are typically prescribed during the mild to moderate stages of dementia. Common cholinesterase inhibitors include donepezil hydrochloride, rivastigmine, and galantamine. These medications work by slowing the breakdown of a chemical in the brain called acetylcholine, which is important for memory and cognition. It does not prevent the build up of plaque, which is one of the causes of Alzheimer's disease. The drug typically relieves symptoms of dementia for 6 or more months, but is a temporary solution (Boyd, 2013).
- **Memantine:** Like cholinesterase inhibitors, memantine (known as Namenda) is also used to slow the progression, and help temporarily alleviate some of its

symptoms, such as forgetfulness. It is typically prescribed to patients with moderate to severe dementia. As brain cells become increasingly damaged, glutamate, which is another type of chemical that is important for memory and cognition, is produced in excess. The extra glutamate can further damage remaining brain cells. Memantine works by regulating the excess glutamate, to temporarily prevent further damage.

- **Behavioral management:** Due to the changes that occur in the brain because of dementia, patients sometimes experience anxiety, depression, and/or psychotic episodes. Although medications meant to target these symptoms were not made specifically for dementia patients, they are sometimes prescribed as “off label,” meaning that they are being used for a different purpose than intended. Antipsychotics should only be prescribed when symptoms are frequent and there is a concern for safety. Because they were not made for dementia patients, they come with an increased risk of death or cardiovascular accident. The use of antidepressants to treat both psychotic and depressive symptoms is controversial due to mixed results in clinical trials (Borisovskaya, Pascualy, & Borson, 2014).

MEMORY AND COGNITION INTERVENTIONS

There are a number of cognitive-linguistic interventions and environmental modification strategies available to individuals with dementia and their families. The following is a brief overview of several of these management options.

- **Memory Aids:** One of the most common strategies to help with memory loss for individuals with dementia is the use of external memory aids. This can be as simple as carrying a to-do list or setting reminders on smart phones (if the patient is familiar with technology). Written reminders can also be posted in different

areas of the house to remind patients of important daily activities such as brushing their teeth at night and in the morning. An ID card should also be placed in the patient's wallet or purse with their name, address, and a contact number in case they get lost. As the disease progresses, episodes of confusion may become more frequent. A person with dementia may lose their orientation to time and place, forget where everyday objects are stored, or lose their ability to navigate familiar places. Calendars and planners may be helpful tools to aid in orientation to time, as patients often lose their ability to identify the month, season, or year (Brookshire, 2007).

- **Environmental Modifications:** Milieu therapy is a popular practice in which the physical and social environment is altered specifically to decrease negative behaviors that are associated with dementia. Some milieu strategies include the use of aromatherapy to aid in sleep, pet therapy to aid in social interaction, and removing distractions from the environment to improve concentration (Grasel, Wiltfang, & Kornhuber, 2003).
- **Reality Orientation:** Reality orientation (RO) is a cognitive therapy technique that benefits individuals with moderate dementia (Zanetti, Oriani, Geroldi, Binetti, Frisoni, Di Giovanni, & De Vreese, 2002). As the name implies, RO is meant to help orient the patient, who might otherwise be confused. Some examples of orientation information include who a person is, the time and date, and place. RO may occur continuously throughout the day with reminders such as "use your clock and calendar" or in a group setting in which individuals discuss current events (Spector, Davies, & Woods, 2000).
- **Spaced-Retrieval Training:** Spaced-Retrieval Training (SRT) is an intervention strategy typically implemented by speech-language pathologists to help dementia

patients remember specific information (Hopper, Mahendra, Kim, Azuma, Bayles, Cleary, & Tomoeda, 2005). The information may be names of objects/people, or may be procedural, such as completing some task or behavior. In naming, a picture of a person or object is presented to the patient along with its name. The patient is then asked to produce the name. After a short period of time the patient is asked to produce the name once more. This continues at increasing intervals of time, until that information can be reliably retrieved. The same can be used for specific behaviors or procedures, such as checking a to-do list.

- **Reminiscence Therapy:** Reminiscence therapy (RT) is an intervention in which the person with dementia recalls past events in his or her life. The intervention can be applied both in individual and group therapy settings. Family members and/or caregivers can also choose to be involved. The person who leads the intervention, typically a speech-language pathologist, will introduce a topic and include supplemental material such as a photograph, music, or prop. The patient then is asked to recall past events and experiences. Some interventions allow the patient to write down these memories, and make a “life book.” This intervention may have cognitive benefits, may improve mood, and can alleviate negative behaviors of the patient (Woods, Spector, Jones, Orrell, & Davies, 2005).

OTHER

- **Support Groups:** Depending on the community in which a patient lives, it may be possible to find support groups for people with dementia or their caregivers. These groups are beneficial for multiple reasons. They allow patients the opportunity to interact with others who are in a similar situation, which can help validate their feelings and experiences. Additionally, people with dementia often

have difficulties communicating, which can lead to withdrawing from social interactions and feelings of isolation (Holmén, Ericsson & Winblad, 2000). These groups may be an outlet for self-expression and a safe community for social interaction. Patients can also participate in clubs that promote cognitive processing, such as book clubs, creative writing classes, art classes, etc.

- **Physical Activity:** A growing body of research suggests that patients with dementia who participate in regular physical activity may see benefits in several domains, including improved physical health, cognition (Heyn, Abreu, & Ottenbacher, 2004), independence in activities of daily living (Vreugdenhil, Cannell, Davies, & Razay, 2012), and a lessening of symptoms of depression (Williams, & Tappen, 2009). Patients with dementia can get exercise through a variety of different activities such as walking, dancing, etc. Of course, exercise should be appropriate for the patient and their medical status should be taken into consideration. Patients and caregivers should discuss exercise routines with their primary care physicians and/or other healthcare professionals.
- **Communication:** As dementia progresses, patients' communication abilities decline. In milder stages, a patient will have difficulty understanding abstract language, such as metaphors, and in moderate stages they will have difficulty understanding more concrete language. They may begin to break eye contact, have inappropriate turn taking, and have difficulty maintaining topic. In the later stages of dementia they may lose the ability to participate in conversational speech and may even become mute. As their communication and cognitive abilities decline, the focus of communication interventions is shifted to caregivers and communication partners. Some effective strategies to help decrease the number of communication breakdowns are: eliminate distractions, speak in simple

sentences, and ask yes/no questions. Caregivers should avoid interrupting and talking slowly to patients (Small, Gutman, Makela, & Hillhouse, 2003).

WHAT ARE FEEDING COMPLICATIONS?

As dementia progresses, it becomes increasingly important for caregivers to monitor the patient's feeding and eating habits. Feeding and eating are defined as two separate activities in healthcare. Feeding is the process in which a person gets food from their plate to their mouth, and eating is the process of getting food from the mouth to the stomach. Although most people do not pay particular attention to feeding as an activity, it is an incredibly complex process. Eating requires the cognitive capacity to recognize that you are hungry, cook or acquire food, and the ability to get that food from plate to mouth. Once food has entered the mouth, a person has to have the sensory and motor ability to chew their food without it escaping and safely swallow it. As dementia progresses and causes damage to the brain beyond regions involved in memory and cognition, a person may lose their ability to complete the steps necessary to maintain nutrition and hydration (Rivière, et al., 2002).

Feeding

In the milder stages of dementia, individuals may forget to eat (Fairburn, & Hope, 1988) or begin to prefer non-nutritious (e.g., sweets) to more nutritious foods (Hope, Fairburn, & Goodwin, 1989). For this reason, it is important for caregivers to monitor the person with dementia for any sudden changes in weight and to determine whether the cause relates to diet or eating habits. As dementia progresses, the affected person may not be able to eat in environments that have many distractions (Durnbaugh, Haley, & Roberts, 1996), such as loud restaurants, or in front of a TV. The act of feeding requires an individual to maintain adequate attention to the food in front of them and use utensils to get that food to their mouth. In later stages of dementia, individuals sometimes lose the ability to sustain attention long enough to feed themselves (Chang, & Roberts, 2008).

They may also lose the ability to recognize and use feeding utensils, such as forks and spoons. In these later stages, the patient will rely increasingly on caregivers to feed them. It is also important to be mindful of the temperature of the food served, as a person with late stage dementia may no longer have the ability to determine when food or drink is too hot and may burn himself or herself. Caregivers should consult with an occupational therapist if feeding behaviors become difficult to manage.

Dysphagia

Dysphagia occurs when a person has difficulty with the act of swallowing food or liquid. Once food is in the mouth, the individual must be able to chew it, push it to the back of the throat, and safely swallow it. The chewed food is called a bolus. Once a swallow is initiated, the throat begins a series of involuntary movements that protect the airway and push the bolus into the esophagus, where it then travels to the stomach. This process relies on a person's ability and strength to control the muscles needed for chewing and swallowing (Exley, 2002). Additionally, their brain must be able to process sensory information, such as the bolus traveling from the mouth to the back of the throat and into the esophagus. When any part of the process is disrupted, a portion of the bolus may go down the airway and into the lungs. This is called aspiration. If untreated, it may result in pneumonia. A physician and/or speech-language pathologist should be consulted immediately if caregivers suspect that an individual is suffering from dysphagia.

ASPIRATION PNEUMONIA

Typically, when aspiration occurs, an individual has the ability to sense it and a reflex cough is initiated. This cough can push aspirated food or liquid out of the airway. Unfortunately, people in later stages of dementia may not be able to initiate coughing to clear their airway and, as a result, food will travel to the lungs (Garon, Sierzant, &

Ormiston, 2009). Even if they are able to initiate a cough, it may not be strong enough to force the bolus out of the airway. When aspiration occurs, food particles can travel to the lungs where they can cause an infection called aspiration pneumonia.

In a study on dysphagia and AD patients, a correlation was found between the severity of AD and the degree of deterioration of the swallowing function and dysphagia (Sato, Watanabe, Edahiro, Sato, Yamane, & Katakura, 2014). In other words, the more severe the dementia, the higher the risk of aspiration. When infection, or pneumonia, from aspiration occurs, the patient can become very sick; fluid could build in the lungs and, in some cases, it can even cause death. In fact, aspiration pneumonia is the most common cause of death in people with dementia (Alzheimer's Association, 2014).

DYSPHAGIA MANAGEMENT

When dysphagia is suspected, a speech-language pathologist will typically perform an evaluation to determine the patient's ability to safely swallow food and liquids of different consistencies (Shipley & McAfee, 2008). A bedside evaluation is typically the first step, in which a speech-language pathologist will look for signs and symptoms of dysphagia while a patient eats and drinks different consistencies, ranging from solid food to thin liquids. If the speech-language pathologist suspects that the patient is aspirating, he/or she may conduct a Modified Barium Swallow Study (MBSS) or a Fiberoptic Endoscopic Evaluation of Swallowing (FEES) to get a more accurate look at what is happening during the swallow. In an MBSS, a patient will eat and drink foods and liquids of different consistencies that have been mixed with barium and an x-ray is taken. This allows the speech-language pathologist to see exactly what is happening to the food and liquid as it is swallowed in real time. In a FEES, the speech-language pathologist will place a thin endoscope through the nose that has a camera and light

attached to it. This camera allows the speech-language pathologist to look into the throat while the patient eats and drinks.

Once it has been determined that an individual has dysphagia, the speech-language pathologist will work with the patient, caregivers, and doctors to determine an appropriate way to manage it (Sura, Madhavan, Carnaby, & Crary, 2012). A patient may have to change their diet to chopped or pureed food, or increase the consistency of their drinks to nectar or honey thick liquids. Postural strategies, such as chin-tuck, and supraglottic swallow maneuver, can also be used when the patient is eating to reduce the risk of aspiration. Although postural movements have been shown to help with the management of dysphagia, it may be a difficult behavior for a person with dementia to remember to use them (Alagiakrishnan, Bhanji, & Kurian, 2013).

TUBE FEEDING

When the risk of aspiration is severe, a speech-language pathologist or physician may recommend that the patient get their nutrition and hydration through tube feeding (Sura, Madhavan, Carnaby, & Crary, 2012). This can take the form of a nasogastric tube, which provides nutrients through the nose, or a gastric tube, referred to as a G-tube, which is inserted at the stomach. Both of these procedures may be temporary, and allow the patient to eat and drink orally, if they should choose to do so. Some caregivers and patients may decide against tube feeding, as this may be perceived as affecting quality of life. It is not uncommon for patients and caregivers to feel that the ability to enjoy food and drink orally outweighs the risk of aspiration pneumonia. Food and drink are often tied to culture and social interactions and when a person can no longer eat, they may experience a decrease in quality of life. For this reason, it is important to take into account not only health considerations, but the quality of life of the patient as well.

WHAT KIND OF ASSISTANCE IS AVAILABLE?

As dementia progresses, the patient's level of independence will gradually decrease. For many, this may mean a shift from living independently to living with a loved one. Unfortunately, not all families are equipped with the knowledge or resources to permanently take care of a person with dementia. Additionally, the stress of caring for a person with dementia may become too great. Many families are not comfortable, or may feel guilty putting their loved ones in nursing homes or long term care facilities. It is important that caregivers know what facilities can help them with the level of care they need, and make the most appropriate decision for themselves and their family.

Adult Daycare

Adult daycare is an option for patients with dementia of mild to moderate dementia severity who live at home with family and/or caregivers. Adult daycare centers offer a safe place for the patient to go during the day while caregivers work, run errands, or relax. These centers typically offer group activities such as exercise classes and games, and provide opportunities for social interaction. Some centers also provide access to physical, occupational, and speech therapists when needed, as well as counseling services. Wilson, McCann, Li, Aggarwal, Gilley, and Evans (2007) followed about 400 adults with dementia who participated in adult daycare before eventually residing in a nursing home. They found that the individuals who attended adult daycare typically had less cognitive decline once admitted to nursing homes compared to those who did not attend daycare. This suggests that it may be an appropriate step in helping patients transition to residential care facilities.

In-Home Health and Respite Care Services

Some families and caregivers may find it more beneficial to have assistance in the home rather than outside of it. In-home health services can range from assistance with the medical needs of the patient, to companionship, to helping with specific tasks (e.g., cleaning and meal preparation) around the house. Medical services are provided by licensed healthcare workers and include administering medications, wound care, and provision of therapy services. Caregivers may be reluctant to get services for help with a patient's daily living activities, but it is important that they consider their own stress levels and quality of life when making such decisions. Respite care is a service similar to in-home health services and adult daycares in that it allows the caregiver to take a break from their responsibilities. These services can be in the home or at a center that caters to the elderly. Although respite care aids may have basic medical training, their main goal is to relieve caregivers of their responsibilities when needed.

Assisted Living Facilities

Assisted living facilities can be a great option for patients with dementia who either do not have family or caregivers they can live with, or who still want to preserve their independence as much as possible. These facilities provide varying levels of assistance with daily living activities, such as transportation, medication reminders, and meals. Additionally, these facilities often offer group activities and opportunities for their residents to socialize. It is important to inquire whether staff is trained and able to assist with dementia patients, as most assisted living facilities are not designed to meet the specific needs of dementia patients, but rather the general needs of the aging population. Assisted living facilities can be a great option for patients who can no longer live independently at home but are not yet ready for a nursing home.

Skilled Nursing Facilities

Skilled nursing facilities (SNFs) are facilities that provide around the clock medical assistance for medically fragile adults who can no longer live at home. A SNF would be appropriate for patients with moderate to severe dementia, who can no longer live at home with their caregivers. As mentioned earlier, many families have a negative outlook on SNFs and may feel as though they are abandoning their loved ones. It is important for the caregivers to assess the skilled healthcare that the patient needs and the caregiver's ability to provide that healthcare. Unfortunately, dementia often progresses to a point that caregivers simply can no longer cope. Like assisted living facilities, it is important to ask about the staff's experience with dementia patients, as every SNF is different. Most facilities provide on-site physical, occupational, and speech therapy. All patients are assisted with ADLs when needed, provided with meals, and have their medication managed.

HOW CAN I TAKE CARE OF MYSELF?

Caring for a loved one with dementia is physically, emotionally, and mentally very difficult. An incredible burden is placed on those who become responsible for an adult with dementia. The management of medical care, finances, and challenging behaviors can be overwhelming. Not surprisingly, 39% of caregivers of adults with dementia experience depression (Pinquart, & Sörensen, 2003). Additionally, Gaugler, Krichbaum, & Wyman (2009) found that the more stressed caregivers were, the more likely they were to put their loved one in a nursing home. It is important for caregivers to get the help that they need, both emotionally and physically. Acton & Kang (2001) conducted a meta-analysis to determine the effectiveness of interventions for caregivers. They found that, although these interventions can help families, they do not necessarily relieve the burden of caregiving. Caregivers should carefully evaluate the type of help they need in order to best meet their goals. The interventions that they studied included the following:

- **Support group education:** Caregivers of people with dementia meet to discuss their experiences, difficulties they face on a day-to-day basis, and possible strategies for dealing with those difficulties. The group setting allows caregivers a chance to meet other people who are going through a similar experience, giving them a sense of community and a source of psychosocial support.
- **Educational Interventions:** Provide information about the nature of the disorder and teach techniques to manage challenging behaviors.
- **Psychoeducation:** Gives the support and community of group education while providing information similar to that of educational interventions.

- **Counseling Intervention:** Focuses on the feelings and reactions of the caregiver toward the person with dementia. Promotes understanding of challenging behaviors to reduce negative feelings toward those behaviors.
- **Respite Care:** An intervention to give the caregiver a break from their responsibilities.
- **Multicomponent Interventions:** Programs that combine two or more of the above-mentioned interventions.

CONCLUSION

As older generations age and life expectancy increases, more and more families will find themselves caring for individuals with dementia. Becoming the caregiver of a person with dementia can be difficult, especially when that caregiver has no background knowledge of the disorder. Signs and symptoms may go unnoticed or be mistaken for the normal aging process. Caregivers may not know how to talk to doctors about dementia or identify appropriate resources to aid in its management.

As dementia progresses, changes in the brain often result in difficult behaviors. It is important that caregivers know which healthcare professionals are trained to work with individuals with dementia and what services they can provide. These healthcare professionals can help to alleviate some of the burdens that caregivers face on a daily basis. People with dementia may benefit from external memory aids, cognitive-linguistic interventions, group activities, and exercise. Along with behavioral changes, changes in feeding and eating may occur that make it difficult for the patient to maintain nutrition and hydration. Feeding and swallowing difficulties may require the use of compensatory strategies, diet restrictions, and even tube feeding. If left untreated, dysphagia can result in aspiration pneumonia, one of the leading causes of death among people with dementia.

The burden of caring for a person with dementia can be overwhelming and frustrating, resulting in mood disorders such as depression, as well as medical problems. There are a number of services and facilities that can help to alleviate these burdens. For patients who want to remain living at home, there are adult daycares, in-home health services, and respite care services. Assisted living facilities are a great option for patients who can no longer live at home but would like to maintain as much of their independence as possible. Skilled nursing facilities are available for patients whose dementia has

progressed into the later stages, necessitating constant supervision from trained healthcare professionals. It is important that caregivers know and understand their options, as there is a high rate of depression and stress among caregivers of adults with dementia. Interventions used to improve caregiver well-being include: support-group interventions, educational interventions, psychoeducation, counseling, and respite care.

Dementia is a progressive and life altering disorder, not only for the patient but for families and caregivers as well. It is important that healthcare professionals educate these caregivers on what to expect and the services that are available to them.

REFERENCES

- Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health*, 24(5), 349-360.
- Alagiakrishnan, K., Bhanji, R., & Kurian, M. (2013). Evaluation and management of oropharyngeal dysphagia in different types of dementia: A systematic review. *Archives of Gerontology and Geriatrics*, 56(1), 1-9.
- Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 10(2), e47-e92.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders, (DSM-5®). American Psychiatric Pub.
- Barnes, D. E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurology*, 10(9), 819-828.
- Boland, R. J. (2000). Depression in Alzheimer's disease and other dementias. *Current Psychiatry Reports*, 2(5), 427-433.
- Borisovskaya, A., Pascualy, M., & Borson, S. (2014). Cognitive and neuropsychiatric impairments in Alzheimer's disease: Current treatment strategies. *Current Psychiatry Reports*, 16(9), 1-9.
- Bourgeois, M. S., & Hickey, E. (2009). *Dementia: From diagnosis to management - A functional approach*. Hoboken: Taylor & Francis.
- Boyd, R. (2013). Early diagnosis and access to treatment for dementia patients. *Nurse Prescribing*, 11(4), 174-178.
- Brookshire, R. H. (2007). Dementia. In R.H. Brookshire (Ed.), *Introduction to neurogenic communication disorders*, 7th ed. (pp. 531-99). St. Louis: Mosby.
- Chang, C., & Roberts, B. L. (2008). Feeding difficulty in older adults with dementia. *Journal of Clinical Nursing*, 17(17), 2266-2274.
- Durnbaugh, T., Haley, B., & Roberts, S. (1996). Assessing problem feeding behaviors in mid-stage Alzheimer's disease. *Geriatric Nursing*, 17(2), 63-67.

- Exley, C. (2002). Swallowing. In D. J. Ekerdt (Ed.), *Encyclopedia of Aging* (Vol. 4, p. 1404). New York: Macmillan Reference USA.
- Fairburn, C. G., & Hope, R. A. (1988). Changes in eating in dementia. *Neurobiology of Aging*, 9, 28-29.
- Federal Interagency Forum on Aging-Related Statistics (U.S.). (2005). *Older Americans 2004: Key indicators of well-being*. Washington, D.C.: Federal Interagency Forum on Aging Related Statistics.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189
- Garon, B. R., Sierzant, T., & Ormiston, C. (2009). Silent aspiration: Results of 2,000 video fluoroscopic evaluations. *Journal of Neuroscience Nursing*, 41(4), 178-185.
- Gaugler, J. E., Yu, F., Krichbaum, K., & Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical Care*, 47(2), 191-198.
- Grasel, E., Wiltfang, J., & Kornhuber, J. (2003). Non-drug therapies for dementia: An overview of the current situation with regard to proof of effectiveness. *Dementia and Geriatric Cognitive Disorders*, 15(3), 115-125. doi:10.1159/000068477
- Gruffydd, E., & Randle, J. (2006). Alzheimer's disease and the psychosocial burden for caregivers. *Community Practitioner*, 79(1), 15-18.
- Heyn, P., Abreu, B. C., & Ottenbacher, K. J. (2004). The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 85(10), 1694
- Holmén, K., Ericsson, K., & Winblad, B. (2000). Social and emotional loneliness among non-demented and demented elderly people. *Archives of Gerontology and Geriatrics*, 31(3), 177-192.
- Hope, R. A., Fairburn, C. G., & Goodwin, G. M. (1989). Increased eating in dementia. *International Journal of Eating Disorders*, 8(1), 111-115.
- Hopper, T., Mahendra, N., Kim, E., Azuma, T., Bayles, K. A., Cleary, S. J., & Tomoeda, C. K. (2005). Evidence-based practice recommendations for working with individuals with dementia: Spaced-retrieval training. *Journal of Medical Speech Language Pathology*, 13(4), xxvii.

- Hyman, B. T., Van Hoesen, G. W., Damasio, A. R., & Barnes, C. L. (1984). Alzheimer's disease: Cell-specific pathology isolates the hippocampal formation. *Science*, 225(4667), 1168-1170.
- Knopman, D. S. (1998). The initial recognition and diagnosis of dementia. *The American Journal of Medicine*, 104(4), 2S-12S.
- Kokmen, E., Naessens, J. M., & Offord, K. P. (1987). A short test of mental status: description and preliminary results. In *Mayo Clinic Proceedings* (Vol. 62, No. 4, pp. 281-288). Elsevier.
- Leifer, B. P. (2009). Alzheimer's disease: Seeing the signs early. *Journal of the American Academy of Nurse Practitioners*, 21(11), 588-595.
- Medications for memory loss. From *Alzheimer's Association*. Retrieved from http://www.alz.org/alzheimers_disease_standard_prescriptions.asp
- Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 58(2), P112-P128.
- Plassman, B. L., Rodgers, W. L., Steffens, D. C., Willis, R. J., Wallace, R. B., Langa, K. M., . . . Potter, G. G. (2007). Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology*, 29(1-2), 125.
- Rivière, S., Gillette-Guyonnet, S., Andrieu, S., Nourhashemi, F., Lauque, S., Cantet, C., ... & Vellas, B. (2002). Cognitive function and caregiver burden: Predictive factors for eating behaviour disorders in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 17(10), 950-955.
- Sato, E., Hirano, H., Watanabe, Y., Edahiro, A., Sato, K., Yamane, G., & Katakura, A. (2014). Detecting signs of dysphagia in patients with Alzheimer's disease with oral feeding in daily life. *Geriatrics & Gerontology International*, 14(3), 549-555.
- Schaie, K. W. (1989). Perceptual speed in adulthood: Cross-sectional and longitudinal studies. *Psychology and Aging*, 4(4), 443.
- Shipley, K., & McAfee, J. (2008). Assessment of Dysphagia. *Assessment in speech-language pathology: A resource manual* (pp. 472-496). Cengage Learning.

- Small, J., Gutman, G., Makela, S., & Hillhouse, B. (2003). Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living. *Journal of Speech, Language & Hearing Research*, 46(2), 353-367.
- Spector, A., Davies, S., & Woods, B. (2000). Reality orientation for dementia: A systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist*, 40(2), 206.
- Sura, L., Madhavan, A., Carnaby, G., & Crary, M. A. (2012). Dysphagia in the elderly: Management and nutritional considerations. *Clinical Interventions in Aging*, 7, 287-298.
- Types of dementia. (2015). From *Alzheimer's Association*. Retrieved from <http://www.alz.org/dementia/types-of-dementia.asp>
- Tzeng, B., & Eisendrath, S. J. (2002). Dementia. In L. Breslow (Ed.), *Encyclopedia of Public Health* (Vol. 2, pp. 311-312). New York: Macmillan Reference USA
- Williams, C. L., & Tappen, R. M. (2008). Exercise training for depressed older adults with Alzheimer's disease. *Aging and Mental Health*, 12(1), 72-80.
- Wilson, R. S., McCann, J. J., Li, Y., Aggarwal, N. T., Gilley, D. W., & Evans, D. A. (2007). Nursing home placement, day care use, and cognitive decline in Alzheimer's disease. *The American Journal of Psychiatry*, 164(6), 910-915.
- Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence therapy for dementia. *The Cochrane Database of Systematic Reviews*, (2), CD001120.
- Vreugdenhil, A., Cannell, J., Davies, A., & Razay, G. (2012). A community-based exercise programme to improve functional ability in people with Alzheimer's disease: A randomized controlled trial. *Scandinavian Journal of Caring Sciences*, 26(1), 12-19.
- Zanetti, O., Oriani, M., Geroldi, C., Binetti, G., Frisoni, G., Di Giovanni, G., & De Vreese, L. (2002). Predictors of cognitive improvement after reality orientation in Alzheimer's disease. *Age and Ageing*, 31(3), 193-196.