



# FLORIDA ALZHEIMER'S DISEASE INITIATIVE

**EDUCATION MANUAL**  
*Understanding & Dealing With Alzheimer's  
Disease & Related Disorders*



Department of  
**ELDER AFFAIRS**  
STATE OF FLORIDA



*Revised May 2016*

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This Education Manual is dedicated to the heroic families who are dealing with the challenges of Alzheimer's disease or related disorders in loved ones.

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# Introduction

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## *Growing National Numbers*

The number of Americans with Alzheimer's disease has more than doubled since 1980. It is estimated that now more than 5.4 million Americans have Alzheimer's disease or some other related severe memory disorder with 11 million people providing unpaid care.<sup>1,2</sup> Even more frightening are estimates that every 70 seconds in the United States someone else is diagnosed with Alzheimer's disease. And the numbers are predicted to reach as high as 16 million by 2050.<sup>1,2</sup>

Some older people have mild difficulty remembering details of an event or recalling names or misplacing items at home; they may or may not get worse over time. This limited decline without difficulty doing one's routine tasks is known as *Mild Cognitive Impairment*, often called "MCI," for short. MCI in some people may reflect the early stages of Alzheimer's disease or a related disorder. Current estimates indicate that about 8 million people in the U.S. have MCI.<sup>3,4</sup>

As the population ages, especially with the large numbers of baby boomers, more people will develop MCI, Alzheimer's disease, or related disorders with an increased impact on society. The impact is especially strong on family caregivers and the many others who provide hands-on services to older people in their homes, residential care facilities, or in community programs.<sup>5</sup>

## *Florida's Growing Numbers Dealing With Alzheimer's Disease and Related Disorders*

In Florida, more than 524,000 people have Alzheimer's disease or a related memory disorder with about 640,000 caregivers providing a value of \$8.4 billion in unpaid care.<sup>1</sup> Those numbers are expected to grow as the number of senior citizens grows and as they live longer.<sup>1,2</sup>

## *Florida's Leadership Addressing Challenges*

In 1985, the Florida Legislature launched the **Alzheimer's Disease Initiative** (ADI), an integrated system of dementia-specific services to address current needs and prepare for the increasing numbers of Florida residents with Alzheimer's disease and related disorders. As a direct result of that vision, today a solid, Florida-wide infrastructure (under the Department of Elder Affairs) provides diag-

nostic and clinical care, education, support, referrals, community outreach, and research for families dealing with Alzheimer's disease and related disorders, though more Floridians than ever need help.

## *15 Alzheimer's Disease Initiative (ADI) Memory Disorder Clinics*

The foundation of the Florida-wide Alzheimer's Disease Initiative (ADI) integrated approach is the ADI network of 15 Memory Disorder Clinics. The 15 ADI Memory Disorder Clinics provide a **continuum of services throughout the entire state** to meet the changing needs of individuals with Alzheimer's disease and their families/caregivers through complete evaluations; treatment; education of family and professional caregivers; research on brain function, the disease process, and possible cures; and strategies to improve care and treatments over the long term.

Responding to the critical, ongoing educational need of families, professional caregivers, and others throughout Florida to have ready access to updated information about Alzheimer's disease and related disorders, care strategies, and helpful resources, a team from the 15 MDCs developed this second edition of the Alzheimer's Disease Initiative Education Manual, available at the following link: [www.eldersaffairs.state.fl.us/doea/alz.php](http://www.eldersaffairs.state.fl.us/doea/alz.php)

## *Purpose of the Alzheimer's Disease Initiative Education Manual*

The purpose of the *Alzheimer's Disease Initiative Education Manual* is to educate people about the basic health changes involved with Alzheimer's disease and related disorders. In addition, basic information discusses how the ability to function changes during the course of disease. The information also suggests practical ways to provide care. Essentially this manual is psychoeducational in that it provides information to help people understand and deal with disorders affecting brain function, in this case people with Alzheimer's disease and related disorders. *This manual is not an approved curriculum and does not meet the statutory requirement for training of agency and facility staff members in nursing homes, assisted living facilities, home health agencies, adult day care centers, and hospice care facilities who have regular contact with or provide direct care to persons with Alzheimer's disease or related disorders.*

Family members and other caregivers of people with Alzheimer's disease face daily challenges to manage the

interactions and care of people with memory difficulties and other thinking problems. As the disease progresses, memory, communication, thinking skills, planning, doing tasks, and self-care get worse and caregivers must do more while the care receiver does less.

As the disease continues, the abilities of the people with the disease may be unpredictable, good one moment and poor the next moment. They may remember what they hear one day and the next day ask the same question over and over. A fact that is explained may make sense one moment and no sense an hour later. Dressing may become difficult without help. Over time, abilities, such as the ability to understand, to remember, to help with tasks, to interact with others, and to provide self-care, become worse.

These health changes may be especially difficult for caregivers to handle. It may be especially taxing for caregivers who try their hardest to prevent decline, yet, over time, the decline continues.

The *Florida Alzheimer's Disease Initiative Education Manual* provides simple information on many topics including the following:

- The brain,
- Ways to communicate to and understand people with progressive dementia,
- Steps to solve behavioral problems and to organize tasks,
- Tips regarding personal care such as help with bathing and dressing,
- Suggestions for activities,
- A discussion of safety issues including driving issues, and
- Ways to reduce caregiver stress.

This manual also identifies some programs and resources in Florida and on a national level that offer information, support services, and other help.

### *Using This Information to Educate Others*

Family caregivers, such as spouses and adult children, and health care providers, such as doctors, nurses, social workers, respite companions, and health aides, learn how to provide information, support, guidance, and comfort to those in their care. In reality this care involves understand-

ing the decline of Alzheimer's disease and related disorders and learning strategies to manage the long-term care. In addition the care not only involves the primary family caregiver, other family members, and health providers, but also neighbors and others in the community. Throughout the continuum of care, there are plans for future needs that the family must consider, difficult decisions to make, and interaction skills and care strategies that must adapt to the ongoing decline of the person with Alzheimer's disease or a related disorder.

Decisions such as long term care, relocation, or even the idea of role reversal may lead to family members feeling guilty, angry, or depressed. Health care providers can provide support, guidance, and comfort to reassure family members that their decision to use extra help is timely and benefits all people involved. These decisions can also impact health care providers and their personal attitudes and feelings about caregiving, coworkers, and family dynamics. This text provides information for families and health providers to use to educate themselves and others. Objectives at the beginning of each chapter can be transformed into questions for use after an educational session to check learning. To stimulate interactive audience participation, the educator or presenter should add examples from the local community or create discussion exercises with open-ended questions, such as asking: "How should we approach this situation?" or "What would you do in the case?" Listings of references and resources offer ways to obtain additional information.

### *Acknowledgements and Appreciation*

The *Florida Alzheimer's Disease Initiative Education Manual* was developed through the teamwork of the Florida Department of Elder Affairs (DOEA), Alzheimer's Disease Advisory Committee Members, and Memory Disorder Clinics. This material represents a major revision of the earlier *Alzheimer's Disease Training Manual* (1996) also developed through the ADI Memory Disorder Clinic team in partnership with many DOEA resource persons.

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- Mary Denise Sparks, PhD, formerly the Director Florida Atlantic University Louis and Anne Green Memory and Wellness Center, Memory Disorder Clinic and currently at the University of Arkansas Medical School, Geriatrics Institute;
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Finally, a special note of appreciation goes to the service, education, outreach, and discovery efforts of the 15 Florida-wide Department of Elder Affairs, Alzheimer's Disease Initiative Memory Disorder Clinics/Centers and Brain Bank listed after the references.

***Thank you all,  
Leilani Doty, PhD***

*Editor: Leilani Doty, PhD  
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Gainesville, Florida (2012)*

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4. Petersen, R.C. (2000). Mild cognitive impairment or questionable dementia? *Archives of Neurology*, 57(4), 643-644.
5. Katzman, R. & Fox, P.J. (1999). The world-wide impact of dementia: Projections of prevalence and costs. In Mayeux, R. & Christen, Y. (Eds.). *Epidemiology of Alzheimer's Disease: From Gene to Prevention*, Heidelberg: Springer-Verlag, <sup>1-17</sup>.

*Florida-wide Department of Elder Affairs,  
Alzheimer's Disease Initiative, 15 Memory  
Disorder Clinics/Centers and Florida Brain  
Bank*

1. **East Central Florida Memory Disorder Clinic** - Melbourne, FL; Phone: 321-768-9575

2. **Lee Memory Care** - Lee Memorial Health System, Fort Myers, FL; Phone: 239-343-2634

3. **Mayo Clinic – Memory Disorder Clinic** - Jacksonville, FL; Phone: 904-953-7103

4. **Memory Disorder Center at St. Mary's** - West Palm Beach, FL; Phone: 561-882-6363

5. **North Broward Medical Center Memory Disorder Center** - Deerfield Beach, FL; Phone: 954-786-7392

6. **Orlando Health Center for Aging & Memory Disorder Clinic** - Orlando, FL; Phone: 321-841-8426

7. **Sarasota Memorial Hospital Memory Disorder Clinic** - Sarasota, FL; Phone: 941-917-7197

8. **Tallahassee Memorial Healthcare Memory Disorder Clinic** - Tallahassee, FL; Phone: 850-431-5001

9. **University of Florida Memory Disorder Clinic** - Gainesville, FL; Phone: 352-273-5550; Clinic Appointments: 352-294-5000

10. **University of Miami Memory Disorders Center** - Miami, FL; Phone: 305-355-9065

11. **University of South Florida Memory Disorders Clinic** - Tampa, FL; Phone: 813-974-3100

12. **West Florida Hospital Memory Disorder Clinic** - Pensacola, FL; Phone: 850-494-6490

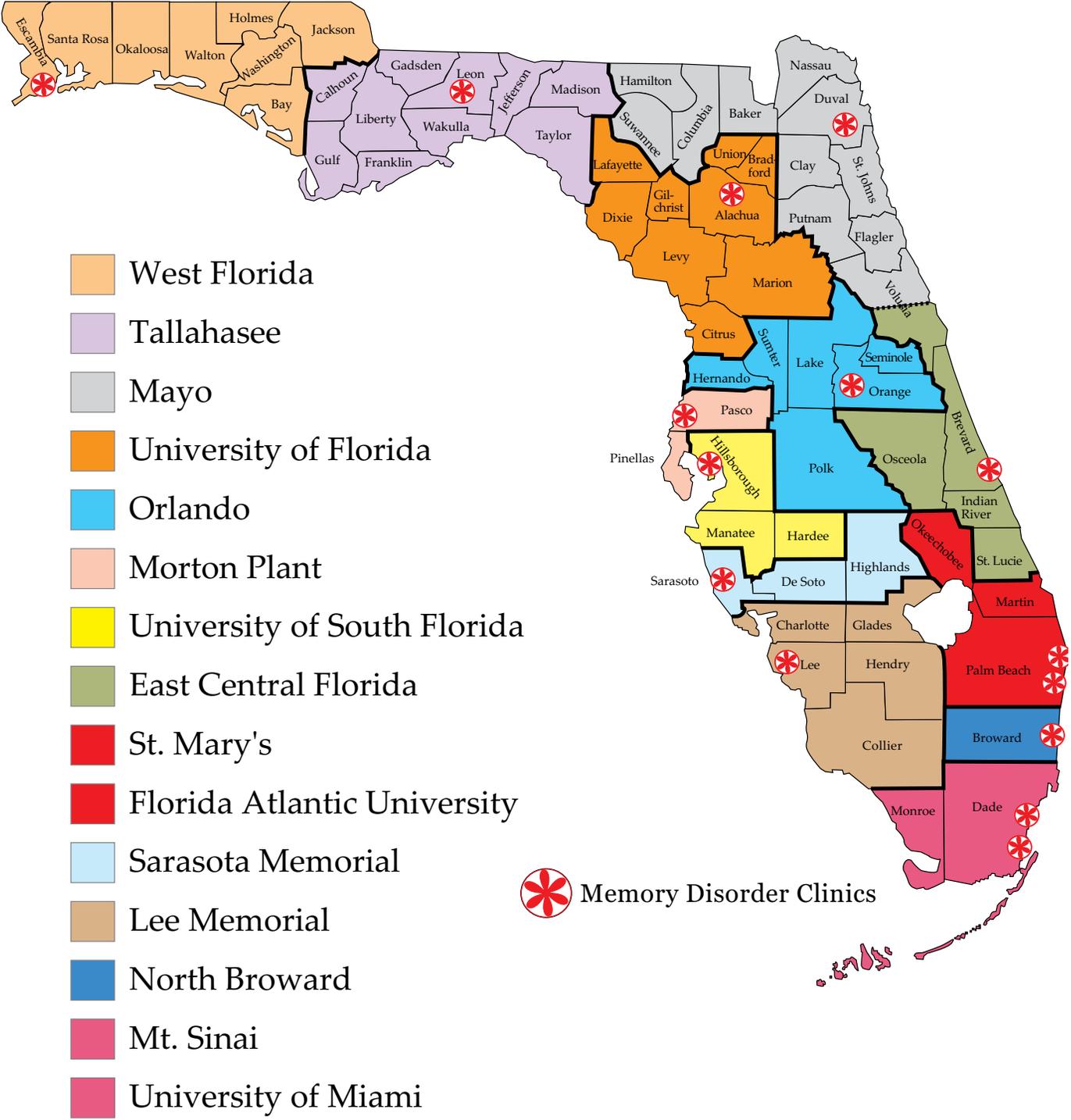
13. **Wien Center for Alzheimer's Disease and Memory Disorders** - Miami Beach, FL; Phone: 305-674-2543

14. **Florida Atlantic University Louis and Anne Green Memory and Wellness Center** - Boca Raton, FL; Phone: 561-297-0502

15. **Madonna Ptak Center for Memory Disorders at Morton Plant Mease** - Clearwater, FL; Phone: 727-461-8244

16. **STATE OF FLORIDA BRAIN BANK** - Phone: 305-674-2018 or 305-674-2543 or 407-843-1910 ext. 308

# Memory Disorder Clinics





# Chapter 1: How the Brain Works

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## **Purpose**

To teach the basics about how the brain works and the normal and abnormal changes in memory as people age.

## **Objectives**

Upon completion of this session, individuals will be able to:

- Identify some normal changes in memory that come with aging.
- Understand the simple basic areas of the brain.
- Know some basic memory and thinking functions of the neocortex.

## **Normal Changes in Memory as a Person Ages**

Healthy older people should be able to receive information into the brain, process it well, and store it or act upon it. This activity may take a bit more effort and a bit more time than when they were teenagers or young adults.

Generally speaking, teenagers and young adults store and recall details of information more readily than people over the age of 65. A typical teenager can easily remember a foreign language or new subject matter, even if the information is new and different from what they have been previously exposed to. Details such as learning a new language; the names of people in a new class; the words of popular songs; and the operation of a new phone, television attachment, or computer are easy for teenagers

to store and recall. When asked a question, the teenager often gives a simple, direct answer.

As people get older, some age-related changes occur in memory ability. People as young as 40 or 50 may begin to feel their memory ability change. In middle-age, new information must have some meaning, value, or be familiar in order for the details to stick easily in the memory system. Many middle-age people begin to use helps such as notes, appointment books, taping conversations or reminders, and grouping similar things together when forming lists. Repeating the details of new information at least a few times helps the new details to stick in the memory. Learning how to play a musical instrument or how to work all the buttons in a new remote control for the T.V. may take some extra time to read about, to practice using, and to learn.

As people mature over the age of 75, there seems to be a slowing of general body processes. It begins to take longer for people to think through details or the steps of a complicated task. They need more time to make decisions and to make new information stick in their brain. They work better when they do one task at a time. Trying to manage several tasks by switching from one task to another may lead to forgetting an important step in one of the tasks. Thus, talking on the telephone while writing down directions may result in missing an important “left turn at Ames Street.”

Research shows that there is a slowing in older people's ability to store and recall information, to shift to a different activity, or to move their body such as when walking. Though the elder may be slower, when asked a question, the rich network of brain cell connections often results in a long answer because their brain links many memories and stories related to the answer for that question.

Older persons can better receive, store, and work with new information by wearing eyeglasses, paying careful attention to a task, and repeating what was just said. Ways to move carefully include thinking and slowing down before acting, such as when going up and down stairs, or sitting down in a chair.

General suggestions to help improve memory include the following:

- Allow enough time and reduce distractions by shutting off the radio, TV, or telephone.

- Focus on one issue or topic at a time.
- Think about the new information.
- Focus on the details of the new information.
- Repeat the new details silently and out loud.
- Link new details to old experiences and memories.
- Practice using the stored information.

When people have new problems struggling to remember what happened or what was said a short time before, then the person should undergo a medical evaluation. There may be a fixable reason for the problem such as stopping a medicine that interferes with good memory or balance. A medical evaluation may uncover a progressive health condition such as Alzheimer’s disease, and the health provider may offer a therapy to optimize function or slow down the decline.

## The Brain

Humans have a **nervous system** which has three basic parts: 1) the **brain**, 2) the **spinal cord**, and 3) the **peripheral nervous system** (the nerves that come from the spinal cord and spread throughout the body). The focus of this chapter is the brain.

### The Brain

The normal human brain is a control center. It controls **automatic functions** of the body such as breathing, heart beats, and digesting food. The brain controls memory and thinking functions such as communication, as well as feelings and emotions. It also controls body movements. The brain controls many other functions that are purposeful (voluntary functions), such as dressing, holding the door open for a friend, or finding a tissue before sneezing.

The brain weighs about three pounds and has many different kinds of cells. There are about 100 billion brain cells called **neurons** and about 10 billion other kinds of cells in the brain to keep the neurons working and healthy. Each neuron has branches called **dendrites** that spread out from its center, the **cell body**. Some dendrites bring signals to the main cell body of the neuron. Other dendrites take away signals from that cell body to the branches of the next neuron.

The tiny area where each branch of one neuron ends and meets the beginning branch of the next neuron is called



**Figure 1 - Healthy Neuron** – Note cell body in the center and connecting branches called dendrites. Image courtesy of the National Institute on Aging/National Institutes of Health, see image at <http://www.nia.nih.gov/alzheimers/scientific-images#brain>.

the **synapse**. There are about 100 trillion synapses in the brain. It is estimated that each neuron has about 7,000 to 10,000 dendrites going to different synapses to connect each neuron to many other neurons.

### Main Sections of the Human Brain

There are three main sections of the human brain: 1) the **cerebrum**, which has a top part called the **neocortex**, often called the cap of the brain, 2) the **cerebellum**, and 3) the **brain stem**.

1. The **neocortex** is responsible for many thinking functions with different areas of the neocortex responsible for activities such as remembering, motivating, planning, problem solving, making decisions and choices, thinking, and feeling. It also controls movement such as speaking, walking, and moving one’s arms to do a task.

2. The **cerebellum** is at the back of the head toward the top of the neck. The cerebellum controls balance and coordination. The cerebellum also controls paying attention to new information and experiences such as seeing a new word when reading or learning something new when talking to a friend.

3. The **brain stem** is at the bottom of the brain, under the neocortex and in front of the cerebellum. It connects the brain to the spinal cord and controls automatic functions such as breathing and blood pressure.

The human brain is divided into right and left halves. Each half has some different special functions and in some cases there is a duplication of function on both sides of the brain. Typically, the left half of the brain controls movement on the right side of the body while the right half of the brain controls movement of the left side of the body. In most people the left side of the brain controls language function and the right side of the brain controls emotions as well as visual spatial function.

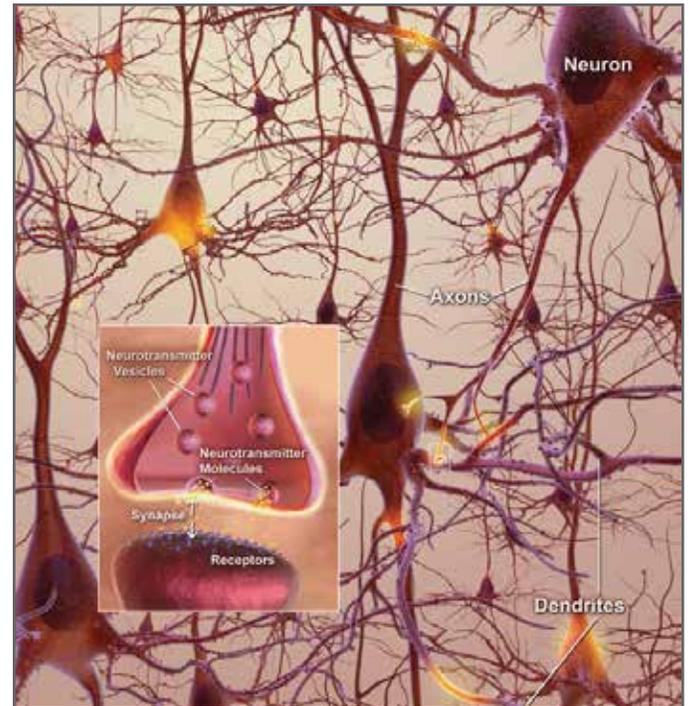
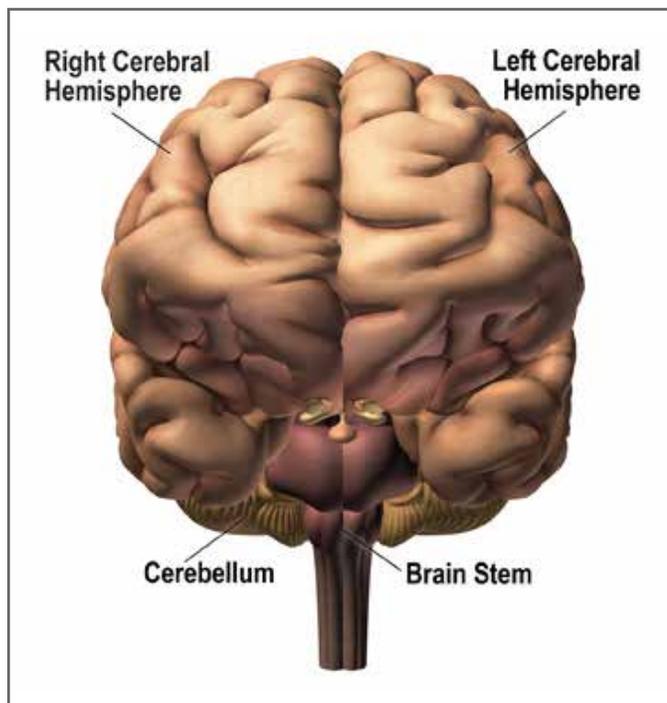
### *Synapses and Nerve Message Chemicals*

Neurons connect to each other through the branches (the dendrites) of the neurons linking at the synapses. The chemicals at the synapses are essential for the movement of information from one neuron to the next. The electrical-chemical charge must go from the end of the branch of one neuron to the branch picking up the signal for the next neuron.

The nerve messenger chemical in the synapses is called

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**Figure 2 - Front View of the Brain**– Note cerebellum at the top of the neck with brain stem going down to the back and spinal cord. Image courtesy of the National Institute on Aging/National Institutes of Health, see image at <http://www.nia.nih.gov/alzheimers/scientific-images#brain>.

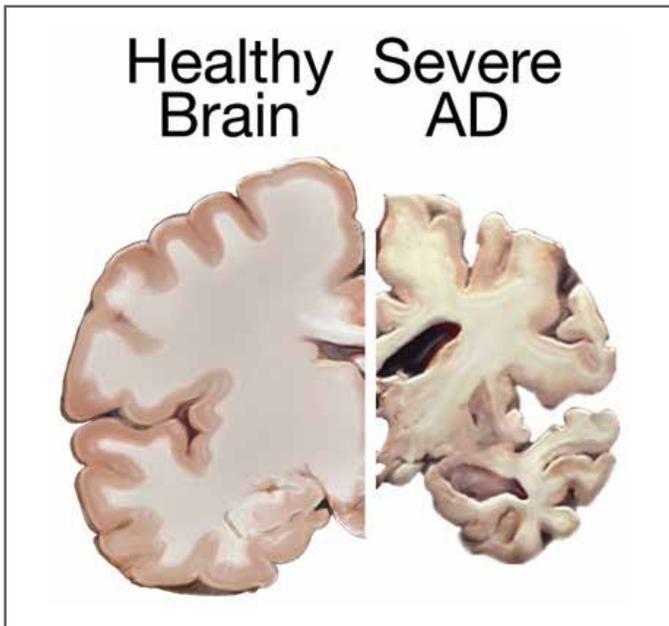


**Figure 3 - Neurons in the Brain** – Note inserted enlargement of synapse showing neurotransmitter (nerve messenger chemicals) moving a nerve signal from the end of a connecting branch (dendrite) on the sending neuron across the synapse (gap) to the dendrite of the receiving neuron. Image courtesy of the National Institute on Aging/National Institutes of Health, see image at <http://www.nia.nih.gov/alzheimers/scientific-images#brain>.

the **neurotransmitter** because it carries or transmits the information from one neuron to the next. The activities of neurotransmitters at each synapse are important for the signal to move from one neuron to the next one.

There are many neurotransmitters. One transmitter called **acetylcholine** has been linked to memory functions because large amounts of acetylcholine occur in the synapses of the brain's memory system. Enough acetylcholine is important for the memory system to function well and also important for some of the other thinking functions such as naming, planning, and making decisions.

Because of the gradual nerve cell loss that occurs in Alzheimer's disease and related dementia, there is less acetylcholine in the synapse. As a result, the signals from one neuron cannot easily cross the synapse to the next neuron. Eventually the decline in synapse activity becomes one of the reasons why neurons weaken and functions, such as memory, communication, and other thinking abilities begin to become difficult.



The figure above compares a cross section of a healthy brain with the brain of someone who had Alzheimer's disease (AD).

**Figure 4 - Healthy Brain and Severe AD Brain** - Note fullness of healthy brain versus empty areas showing loss of brain cells (neurons) in brain with Alzheimer's disease. Image courtesy of the National Institute on Aging/National Institutes of Health, see image at <http://www.nia.nih.gov/alzheimers/scientific-images#brain>.

With more and more damage to the nerve cells, these cells continue to weaken. After a while the brain cell decline shows up in major problems such as not remembering to do routine tasks on the job and at home. For example, the person may fumble at tasks which were done easily and quickly on the job or at home. The person may become unable to complete simple tasks such as putting together a sandwich, finding a coat and putting it on, or finding a letter which they planned to mail. The general term for the decline in memory or thinking function is called **dementia**.

### **Dementia**

Dementia is the decline of any mental abilities while the person is awake and alert to the point of interfering in the ability to do one's daily tasks and interact well with others. Dementia is not a normal part of aging. It may result from hormone imbalance, poor nutrition, a one-time event such as a small stroke or several small strokes that affect the memory area of the brain. Typically a large stroke causes dementia or the accumulative damage from several smaller strokes.

The decline may get slowly worse over time and lead to Alzheimer's disease, a related disorder such as vascular dementia often connected with strokes, or a mixture of dementias such as Alzheimer's disease combined with vascular disease.

The decline of dementia may weaken memory, knowledge, decision skills, and/or communication. The decline may change the ability to do daily chores such as driving the car, cooking, playing a game with grandchildren, or running a regular meeting. The dementia may lead to a change in personality.

People with dementia may have difficulty with tasks that were once easy for them to do. They may forget names or whether they just had breakfast. They may forget the way home from the grocery store though they have used the same route for many years.

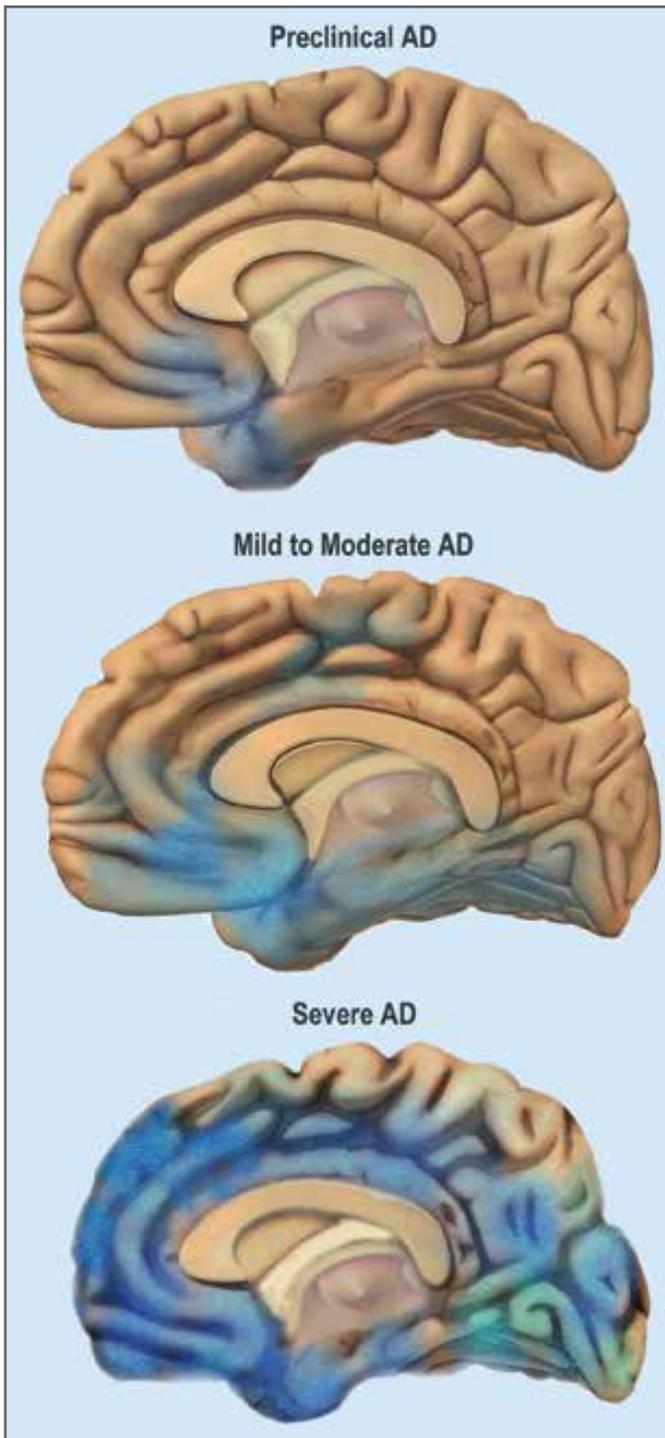
Changes in memory ability or in the ability to think and do daily activities may indicate changes in general health, which may eventually impact brain health. For example, developing high blood pressure or diabetes impacts the blood vessels and circulation in the brain. Such changes in the brain may lead to tiny strokes which may build up over time and result in a vascular dementia.

A full medical exam when there are early signs of decline may point to a diagnosis of a fixable dementia. Or, it may point to a progressive dementia such as Alzheimer's disease or a related disorder, which may benefit in some way from treatment.

### **Keeping the Brain Healthy**

Important to keeping the brain healthy is a healthy lifestyle. Covered in more depth in a later chapter, the brief points of a healthy lifestyle include the following:

- Drinking enough water every day;
- Eating a healthy diet, especially fresh fruits and vegetables;
- Social exercise: having good interactions and activities with other people;
- Avoiding harmful products such as tobacco and too much alcohol;
- Physical exercise every day;
- Brain exercise every day;



**Figure 5 - AD Spreads Through the Brain** – Note in the above three middle side-section-views of the brain. The increasing amounts of blue color from the top section (Pre-clinical AD) to the bottom section (Severe AD) show the slow loss of neurons over the years as Alzheimer’s disease spreads in the brain. Image courtesy of the National Institute on Aging/National Institutes of Health, see image at <http://www.nia.nih.gov/alzheimers/scientific-images#brain>.

- Spiritual health;
- Reducing stress; and
- Having regular medical and dental check-ups and following recommended care.

## Summary

While the younger (teenage) brain remembers details easily, as people become older adults, age-related changes occur in memory, communication, and other thinking abilities. People in their 40s or 50s may need to attach some meaning, value, or familiarity with new information to help them remember it. In their 70s, people begin to slow in mental processes, thus it takes more time to store information and more time to recall information (details). Tips to help memory include the following:

- Allow enough time and remove distractions.
- Think about the new information.
- Focus on the details of the new information.
- Repeat the new details silently and out loud.
- Link new details to old experiences and memories.
- Practice using the stored information.

## The Brain

The brain has about 100 billion neurons and about 10 billion other support cells which work to control various functions in the brain and body. Some of these functions include the following:

- Automatic functions such as breathing, heart-beat, and digestion;
- Movement such as walking, picking up and carrying an object; and
- Thinking functions such as understanding and expressing speech, reading, and organizing an activity.

Each neuron has a cell body with branches (dendrites) that carry signals from one neuron, across a gap (called a synapse) to the next neuron. Acetylcholine is one of the chemicals in the brain that is important for memory and other brain functions.

*Three major sections of the brain are:*

1. The **cerebrum** which manages memory, language, choosing, planning, and directing actions of the body such as using a pencil to write a note;
2. The **cerebellum** which controls balance, coordination and paying attention to new information such as being introduced to a new person; and
3. The **brain stem** which connects the brain and spinal cord and controls automatic functions such as breathing and blood pressure.

## ***Dementia***

Dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home. Changes in memory ability may indicate changes in general health, which may eventually impact brain health. Any changes in brain function should lead to a medical evaluation.

A full medical evaluation may point to a treatable condition or a progressive condition such as Alzheimer's disease or a related disorder with treatment recommendations. No matter what the results, it is important to develop a daily healthy lifestyle, by doing the following:

- Drinking enough water every day;
- Eating healthy foods especially fresh fruits and vegetables;
- Exercising: physical, social, spiritual, and brain;
- As much as possible, avoiding tobacco and alcoholic beverages;
- Avoiding, if possible, or reducing unpleasant stress; and
- Having regular medical and dental check-ups and following the resulting recommendations.

# Chapter 2: Daily Health Tips

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## Purpose

To briefly describe basic tips in a healthy daily routine to keep persons with Alzheimer's disease or related memory disorders and their caregivers functioning as well as possible.

## Objectives

Upon completion of this session, individuals will:

- Understand nine areas of the daily routine that impact health.
- Know important behaviors to keep a person with Alzheimer's disease or a related memory disorder as healthy as possible and functioning as well as possible.
- Know important behaviors to keep family and paid caregivers as healthy as possible and functioning as well as possible.

## A Healthy Lifestyle Can Make a Difference

A healthy lifestyle is especially important for the whole body to work well. People with a healthy lifestyle will function better by keeping up with daily healthy habits, even when there is a diagnosis of Alzheimer's disease or a related memory disorder.

A healthy lifestyle keeps the nervous system functioning as well as possible. The brain, the spinal cord, and the nerves throughout the body make up the nervous system. When the brain cells suffer from the decline of a progressive dementia such as Alzheimer's disease, it becomes especially important to keep up with daily health habits in order to help the brain cells to function as fully as possible and for as long as possible. Healthy daily routines are important also for family and paid caregivers.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to ongoing decline over time. Though Alzheimer's disease is the most common progressive dementia, many other types of dementia exist.

A healthy lifestyle includes drinking enough water every day, good nutrition, regular physical and brain exercises, daily activities of interest, having a sense of purpose in life, feeling valued, good relationships, and as little negative stress as possible.

Not only do unhealthy behaviors such as poor eating habits and lack of exercise weaken brain cells but also unexpected changes in general health can interfere with brain cell function. Health issues such as hormone changes, infections, and chronic pain such as that of the back or joints can impact brain function. Changes in blood flow from chronic high blood pressure or poorly controlled diabetes and other similar conditions also can affect brain function. Such conditions may lead to declines in memory and thinking abilities. In addition, neglect of these conditions can make functional difficulties worse in people with progressive dementia.

## Basics of Daily Health

- Enough water every day: 10 to 12 glasses of water or similar liquids unless a physician restricts fluids
- Good nutrition, especially grains, fresh fruits, and vegetables every day
- Exercise (both physical and brain) and other activities
- Sense of purpose
- Feeling valued (sense of worth)
- Positive relationships
- Reduced negative stress

- Healthy sleep
- Regular medical and dental checkups

Regular medical checkups can identify health problems, often when they begin. Early treatment of health problems and daily healthy lifestyle habits can improve brain functions and can keep the memory and other thinking functions working better. The basics of daily health are listed in the previous section, Basics of Daily Health and are discussed in detail in the following section:

### *Drinking Enough Water*

People should drink 10 to 12 glasses of water or a similar liquid every day unless a physician limits liquids. When people do not drink enough water, the body is at risk for infections and other ill effects such as stroke. Drinking enough liquid is important for a healthy brain.

Dehydration is one of the conditions that can lead to being light headed or dizzy, or having a stroke. People with Alzheimer's disease may forget to drink enough liquid or may not be aware of feeling thirsty. Therefore, the caregiver should offer a drink of water after each meal and throughout the day.

In general, people should limit alcoholic beverages. On a daily basis (with a meal) women should drink no more than four ounces of wine and men should drink no more than eight ounces of wine. People who have problems with memory or other thinking functions, such as communication or decision-making, should avoid alcoholic drinks. Heavy alcohol use can damage brain cells and their ability to function.

Fresh fruits and vegetables, fruit juices, soups, and jello are sources of liquid. It is always important to ask the physician (or other health provider) and pharmacist whenever taking a new medicine to learn about related diet or liquid restrictions.

### *Healthy Eating for the Body and the Brain*

The nervous system and especially the brain need good nutrition every day. Good nutrition involves eating healthy foods such as:

- Fresh fruits and vegetables, especially ripe ones with strong, bright colors;
- Whole grains (such as wheat, barley, oats, maize, brown rice, and rye);

- Legumes, such as beans, peas, and lentils which include black beans, lima beans, fava beans, chick peas, black-eyed peas, small lentils (of various colors), and edamame which are green, soft baby soy beans
- Protein such as meat, fish, eggs, lentils, and peanuts;
- Monounsaturated fatty acids (such as olive oil, safflower oil, or corn oil, and nuts such as peanuts); and
- Omega-3-fatty acids (polyunsaturated fats), such as in salmon, olive oil, flaxseeds, hemp seeds, walnuts, almonds, and soybeans.

### *Healthy Meals and Snacks*

Each day should start with a healthy breakfast with regular meals to keep the brain working well throughout the day. To help keep people with Alzheimer's disease well-nourished, small snacks should sit in a handy place such as on the kitchen table. Snack suggestions are ready-to-eat finger foods, such as bite-size chunks of cheese, small biscuit sandwiches filled with meat and vegetables, berries, small pieces of vegetables, or small pieces of peeled fruit such as sections of an orange or chunks of peaches or bananas.

### *Some Cautions*

While healthy foods lead to a healthy body and brain, people should apply common sense and eat a balanced, sensible diet. Even too much of a healthy food can lead to problems. For example, people who drink too much carrot juice can get too much Vitamin A. Taking too much concentrated Vitamin C such as in pills can irritate the kidneys and the bladder. An irritated bladder may result in urine urgency (a strong need to urinate), frequency (urinating too often), and leaking (wetting one's clothes).

Caution should be exercised with some fruits like grapefruit which may result in some reactions with cholesterol-lowering medicines. Some vegetables such as broccoli or spinach, which are high in Vitamin K, can work against the effect of anticoagulants. [Anticoagulants are blood thinners such as heparin, Coumadin (also called warfarin), or aspirin.]

Scientists have identified unsafe chemicals and waste materials, such as mercury and other toxic chemicals, in bodies of water such as lakes, rivers, and oceans where fish

thrive. As a result scientists caution people to eat fish only once or twice a week. The fish should come from “clean” waters.

## *Exercise*

Everyone needs physical and mental exercise. Regular physical exercise at least five days a week is important while brain exercise should occur every day. The daily schedule should include enjoyable activities that include time with others and time alone in ways that add to the quality of life. (Suggestions for physical activities are described in a later chapter.)

## *Physical Exercise*

Physical exercise for at least 30 minutes at a time for at least five days a week helps the whole body. The exercise should be vigorous enough to work up a light sweat on the skin.

Regular physical exercise helps control weight, strengthens bones and muscles, boosts the immunity system, relieves stress, lowers blood pressure, and helps blood circulation. People with anxiety and depression often feel better after exercise.

Research shows that physical exercise not only sends good blood flow throughout the body but also to the brain. In addition, physical exercise stimulates the repair of brain cells and the growth of new brain cells.

Physical exercise also offers protection to the brain cells. The increase of nerve growth factors from physical exercise enhances the life and growth of different brain cells. Exercise releases the substance brain-derived-neurotrophic factor, which helps keep brain cells and their connections healthy. Brain-derived-neurotrophic factor thus can benefit memory and thinking functions.

Different activities count as exercise. Exercise may involve a task such as doing housework, chopping vegetables for a salad or soup, washing and waxing the car, or scrubbing porch furniture. Or, exercise may involve fun activities such as walking, biking, light jogging, chasing grandchildren, playing tennis or other sports, or stretching and using weights at a gym.

Exercise and activities for people with Alzheimer’s disease should be enjoyable and a positive experience for the others who are involved. Positive, simple activities should occur on a routine schedule with a small amount of

variation just to add something new. For example, when walking one should follow the same path in the neighborhood, the park, or an indoor shopping mall. A nice routine may be a daily mid-morning walk with a caregiver or friend followed by a rest stop for a drink of water on a favorite park bench. Resting on a bench provides an opportunity for people-watching or bird-watching. Add variety by noticing and discussing a different flower or bush in the setting during a walk and varying the liquid refreshment after the walk. When walking in an indoor shopping mall, resting on a bench by a pet store window that shows animals at play can add some variety and entertainment to the routine activity.

## *Brain Exercise*

**Memory Function:** Memory ability is sharpest during the first twenty-five years of life. However, the healthy brain can reorganize, grow connections, and store new information throughout life, a process called brain plasticity. Memory for facts and new details, such as an appointment times or the names of people, is stored in the memory system of the brain. In a different brain system are the memories for routine, well-learned activities, such as how to open a door, how to dress, or how to drive a car.

Our sense systems (for example: smell, taste, touch, hearing, and seeing) hold memories. Some people have stronger visual memory (forming memory-pictures in their brain). Some people even have photographic memory. Others have better memory when they hear information (aural memory) or feel the object in their hands (tactile/touch memory).

When a life experience triggers a sense system, memories related to those senses rise up into a person’s level of awareness. For example, the smell of chocolate may bring back memories of chocolate cake at family birthday parties. Holding and smelling hay may stir up memories of early youth and life on the farm. Seeing an antique car may stir up memories of the family car from one’s teen years.

As people become older, sometimes as early as in their 40s or 50s, they begin to forget small details or need a few minutes for those details to come to mind. It may take several minutes or, when they are older, a few hours to recall details such as names and facts. It takes more conscious effort for people in their 70s and older to gather, learn, and recall details.

Occasional forgetfulness such as forgetting why you went into a room, forgetting the item you want to buy at the store, or forgetting a few details from the movie you saw yesterday is normal. Not paying attention, not hearing well, not seeing clearly, worry, anxiety, or depression can interfere with memory. To remember important details, people should do the following:

- Work hard to pay attention,
- Write down the facts,
- Listen (turn up hearing aids if needed), and
- Wear the right eyeglasses (or contact lenses).

**Brain Function and Related Exercises:** Mental exercise every day is vital to keep memory and thinking abilities sharp. We really do need to use it or lose it. (Suggestions for brain exercises for memory and other thinking functions are described in a later chapter of this curriculum.)

Variety in brain exercise keeps the connections between brain cells active and helps to increase the number of brain cell connections. Just as a tree in springtime sprouts new branches, brain cells with the proper stimulation can grow new branches (new connections). The expanded number of brain cell connections may increase the chances of the brain functioning better and longer even when poor circulation or weakening cells in the brain tissue result in decreases in thinking and memory abilities. The extra connections act as back-up cells to the brain. Essentially the back-up cells form a brain reserve (sometimes called a cognitive reserve).

Examples of simple brain exercises for people with progressive dementia such as Alzheimer's disease follow:

- Language exercise (recalling words): crossword puzzles that use just a few, small words (words with three or four letters at the most);
- Language exercise (understanding and expressing words): visit and talk with one or two friends in a quiet setting;
- Language exercise (reading) and visual-spatial exercise (looking for the correct number) and motor exercise (arm and fine finger movement): bingo cards with large numbers or pictures that a person can cover with marshmallows, pieces of cereal, or small salt-free crackers such as oyster or goldfish;

- Visual-spatial exercise: jigsaw puzzles that use a few, large, thick pieces that are easy to pick up, such as children's wooden puzzles;
- Visual exercise: use of nontoxic glue to attach small pieces of paper, fabric, shells, or other materials to colored paper;
- Memory (short-term) exercise: Put two or three objects such as a spoon, a pencil, and a book (or more objects if the short-term memory is better) in a box, say the names of the objects, cover the box to hide the objects, and talk about anything else for one minute (or more if the person's memory is better). Then try to recall the names of the objects that are hidden in the box.
- Memory (long-term) exercise: Put in an open box some items that were used long ago, when the person with Alzheimer's disease was a child or young adult, for example, old-fashioned clothes or pictures of an old car, a penny postcard, or an old dial telephone. Have the person describe the item and memories from their early years when that item was part of their life.

### *Value of Change in Brain Exercise*

Change exercises the brain. While routine helps the person with Alzheimer's disease, a small change in the routine may offer good stimulation. For example, consider doing the following:

- Eat breakfast or lunch at the routine time but in a different room or outside on the patio;
- Go for a routine walk at different time of the day;
- Add some new hand gestures to a well-known song;
- Buy a new collar of a different color to put on a pet cat or dog; or
- Try a new kind of bread, fruit, or vegetable.

Also, good for the brain are working on enjoyable projects such as working in a garden, making simple crafts such as simple stuffed pillows, or sanding and painting small colored blocks for children.

## *Sense of Purpose*

A sense of purpose grows from feeling like a meaningful contributor to others, having a sense of control over actions, and accomplishing something. *An Archives of General Psychiatry* (2010) report of research led by Patricia Boyle, PhD, showed that having a sense of purpose in life may reduce the risk of developing Mild Cognitive Impairment (primarily a short-term memory problem) and Alzheimer's disease in 951 older people (average age of 80.4 years) who lived in the community.

When there is a clear reason to do a task, there is a sense of purpose in approaching a task. When there is a clear reason to live each day, then there a sense of purpose in starting each day and doing the daily activities. Understanding the value of a task helps to interest a person in starting and completing the task. Understanding involves knowing the “who, what, why, when, or where” details of a task and may boost the drive to do the task.

Typically having a sense of purpose and the drive to work on a task and toward a goal rises from within the person. Scientists indicate that the frontal lobes of the brain (within the skull behind the forehead) control internal drive. With some progressive dementias such as frontal (lobe) dementias and with later stage Alzheimer's disease, the brain cells that control one's drive become weak. As a result, the drive to do a task often must come from outside the person, in other words, from someone else such as a family caregiver or paid caregiver.

One way to set up outside drive is to create a daily and weekly schedule on a piece of paper that is highly visible, such as posted on a bulletin board or on the refrigerator door. Another strategy is to set up a simple reward system. For small accomplishments, the person with dementia can follow one or two steps of directions, and then receive praise for the accomplishment before receiving directions for the next step. Step by step, they gain a sense of doing and accomplishing. As a result, they build a sense of purpose.

Knowing about and keeping a list of rewards that work can move a person forward on small steps of a task. The sense of purpose may depend on focus on a reward. For example, frequently reminding about the reward of listening to music or wearing a favorite shirt after bath time may help the person with progressive dementia get through bath time.

Caregivers should think about the current skills of the person with progressive dementia and how the skills may be applied to help with small steps of daily tasks.

## *Feeling Valued (Sense of Worth)*

A sense of value may be built up by not only doing useful tasks, but also by being recognized for helping others. In receiving recognition for helping, a person may feel respected by others and build a sense of worth.

People feel valued when they make a meaningful contribution to others or when they help in some way and receive appreciation for their efforts. People with progressive dementia can help with simple one-step tasks such as handing an eating utensil or napkin to someone. Recognition for a single step of help is a way for the person to feel valued as a member of the family unit or a group at a community program.

Feeling worthwhile and capable helps people to feel valued and encourages their participation in doing daily tasks. Caregivers and program staff can help a person with a progressive dementia such as Alzheimer's disease feel valued by applying some of the following techniques:

- Use “please” and “thank you”;
- Talk with words of praise such as: thanks for your help, you did a great job, or (more specifically) thanks for carrying that piece of paper to the trash can;
- Each time you see the person, smile and say something positive;
- Give a nod of the head;
- Pat the shoulder or the forearm; and
- Listen with eye-to-eye contact and give a positive facial expression.

Small items may serve as rewards or motivators: a new picture from a magazine, a past photo of the family, or a kind word.

## *Positive Relationships*

Positive interactions with family and friends help to keep thinking functions healthy. Having a spiritual relationship and a spiritual community especially to help with some of life's challenges seem to contribute to better functioning and better mental health. Positive relationships with

others also boost the thinking abilities of people with progressive dementia. Feeling respect from others helps a person with Alzheimer's disease feel a sense of connection to them.

Shared positive experiences strengthen the sense of belonging even when the person with progressive dementia does not remember the names of other people or recognize the identity of loved ones. The positive interactions can help the person with progressive dementia to keep a sense of being welcomed, feeling wanted, and receiving good care. Over time their positive interactions will maintain the sense of familiarity and feeling connected. Caregivers may build positive interactions with people who have a progressive dementia by doing the following:

- Providing ongoing support;
- Being patient;
- Making positive remarks to the person;
- Using praise;
- Being generous with compliments;
- Showing caring with a pleasant voice and happy facial expression; and
- Acting with respect by calling the person by name, getting the person's attention before talking, listening carefully, and reflecting words back so the person knows he or she was heard.

When feeling tired, frustrated, or irritable, caregivers should take a break for a few minutes, approach the person and the task in a different positive way. Soon after, the caregiver should schedule time for respite.

### *Relieve Stress*

Ongoing unpleasant (negative) stress is unhealthy for the brain. Chemicals that the brain releases during stress can interfere with memory and other thinking abilities such as planning and doing tasks. Examples of ongoing negative stress are as follows:

- Dealing with unpaid bills;
- Lifestyle changes such as changed roles or a job that adds more tasks;
- Family members who cause lots of worry;
- House repairs or car accidents;

- Physical health problems of oneself, loved ones, or family pets;
- Loss of income;
- Safety issues in the neighborhood; and
- Being exhausted.

These and other stressors can lead to problems with memory, communication, and thinking such as difficulties making plans, decisions, or completing a task. Regular exercise such as walking or doing yard work may reduce stress. Sometimes it is possible to spend less time with people outside the family unit who drain one's physical and emotional energy. Some relief may come from having family help with minor repairs or having friends work together to improve neighborhood safety. Activities such as yoga or tai chi help to reduce stress.

For continuous long-term stressors such as caregiver stress, resources such as respite care or volunteer sitters may free up time for some caregiver "down time." A support group may offer listening, empathy, and simple tips to reduce stress.

### *Healthy Sleep*

Getting enough sleep and healthy sleep are important for good brain function. During good sleep, the person goes through stages of light and deep sleep. Going through the full cycles of light and deep sleep are necessary for good memory storage (called memory consolidation). In addition to full sound sleep being important to firm up memories from the daytime activities in the brain, the sleep allows for repairs to occur throughout the body.

During good sleep, certain areas of the brain release leptin. Healthy amounts of leptin in the brain decrease our craving for foods that are high in fat or sugar.

Restless sleep may link to late snacks of heavy foods or drinks containing caffeine. Stimulating activities just before bedtime such as T.V. mysteries, paying bills, or arguments activate instead of relax the person. Breathing problems during sleep such as sleep apnea and different causes of insomnia interfere with healthy sleep.

### *Sleep Apnea*

It is estimated that in the United States more than 12 million adults have sleep apnea. Sleep apnea occurs when there is blocking of the upper part of the airway dur-

ing sleep and the person stops breathing for a brief period of time. The periods of time may be long enough to interfere with enough oxygen getting into brain cells. This problem may lead to memory difficulties, increased risks for stroke, and possible vascular dementia.

After a medical diagnosis of sleep apnea, treatment may involve weight loss, throat exercises, and/or CPAP. A CPAP is a breathing mask and machine that provide continuous positive airway pressure during sleep and allow for good sleep. More information about sleep apnea is available through the American Sleep Apnea Association ([www.sleepapnea.org](http://www.sleepapnea.org)).

### *Insomnia*

There are two basic types of insomnia: 1) difficulty falling asleep and/or 2) difficulty staying asleep. Sleep difficulties may lead to problems with memory, other thinking functions, and other health problems.

Some people have sleep onset latency (trouble falling asleep). For example, it may take 30 minutes or more to fall asleep. Once asleep, they sleep well.

Other people fall asleep easily but have trouble staying asleep. Thus, after the first full 90-minute cycle of sleep or after the second 90-minute cycle of sleep, they cannot stay asleep. They may use the bathroom and then dress and act ready to start the day though it is only 3 a.m. Sleep hygiene may lead to good sleep.

### *Sleep Hygiene*

Healthy sleep habits are called sleep hygiene. Tips for good sleep hygiene include the following:

- Sticking to a regular routine for going to sleep and waking up;
- Not taking long naps or not napping after 3 p.m.;
- Getting early morning exposure to about 30 minutes of sunlight to help set the day-night sleep cycle; (The bright sunlight gets the body alert and helps the pineal gland in the brain to hold back the hormone melatonin which makes people sleepy.);
- Exercising enough for your body to build up fatigue; and

- Keeping the bedroom at a comfortable temperature, clutter free, and quiet;
- Lowering the light in the bedroom so that it is dark enough, though a small night light may help nighttime bathroom visits;
- Relaxing a few hours before bedtime to help the body and brain to “wind down” from the day’s activities and stress;
- Taking a warm bath or warm foot soak to relax before bedtime;
- Not having caffeine several hours before bedtime; and
- Not having heavy snacks before bedtime.

Further information regarding sleep and sleep disorders is available from the following:

- American Academy of Sleep Medicine: sets standards for sleep disorders and identifies accredited sleep centers or labs, [www.aasmnet.org](http://www.aasmnet.org)
- American Sleep Association: improving public awareness about sleep disorders and sleep health, [www.sleepassociation.org](http://www.sleepassociation.org)
- American Sleep Disorders Association: information on sleep disorders, [www.asda.org](http://www.asda.org)
- National Sleep Foundation: information on sleep health and safety, [www.sleepfoundation.org](http://www.sleepfoundation.org)
- Sleep Research Society: information on all aspects of sleep, [www.sleepresearchsociety.org](http://www.sleepresearchsociety.org)

### *Regular Medical Checkups*

A short-term memory loss and any thinking problems need a full medical evaluation as early as possible. A heart problem, diabetes, blood pressure problems, low levels of vitamins or hormones, and chronic infections are a few of the changes that can affect brain health. Chronic tooth and gum problems can lead to poor nutrition or the spread of infections, both of which can impact brain function. Chronic, untreated anxiety and depression can contribute to memory problems.

Many of these changes are fixable. Some of them can be treated so that the injury to the brain occurs more slowly. Some of the progressive disorders that are not curable

such as Alzheimer's disease may benefit from treatments that help the brain to work better.

### *Medicines May Hurt or Help*

The purpose of prescription medicines and over-the-counter medicines are to improve health and function. However, some of these necessary medicines may interfere with healthy brain function, such as with memory. For example, while antihistamines treat allergies, cold symptoms, or dizziness, antihistamines typically cloud memory and other brain functions.

### *Ask about Medicine Effects!*

Before starting a new medicine, a person should ask the doctor (or other health provider such as a nurse practitioner) **and** the pharmacist whether the medicine interferes with memory, sleep, food, liquids, any other medicines the person already takes, or other abilities to function well. It is just as necessary to ask about over-the-counter medicines as it is to ask about prescription medicines.

## Summary of Healthy Living

A healthy lifestyle may be able to improve memory function or maintain the current level of memory function. Following recommendations for a healthy lifestyle will promote the best level of brain function even when there is a diagnosis of a progressive dementia such as Alzheimer's disease.

### *Basics of Keeping the Brain Healthy*

- Good nutrition: grains, fresh fruits, and vegetables every day.
- Ten to twelve glasses of water a day unless a physician limits liquid intake.
- Regular physical exercise, at least 30 minutes at a time for five days a week.
- Daily brain exercise: crossword & jigsaw puzzles, word scrambles, math puzzles, listening to music, singing songs, playing an instrument, etc.
- Regular positive interactions with others.
- Activities for spiritual health.
- Daily meaningful tasks and enjoyable activities.
- Low levels of negative stress.
- Healthy sleep.

- Following medical and dental advice to take care of your health.

A healthy lifestyle includes good nutrition, drinking 10 to 12 glasses of water or suitable liquids each day unless a physician limits liquids for health reasons. Also important are daily physical exercise, daily brain exercise such as doing crossword puzzles, reading and discussing the reading material, and trying to learn something new every day; visiting regularly with friends; doing meaningful and useful tasks; working on enjoyable projects; doing fun activities; and keeping down levels of negative stress such as from family conflicts or unpaid bills.

Regular medical and dental check-ups are important. As important, however, is to follow treatments and other health recommendations.

Doing various activities and interacting regularly with family and friends keep the brain cells stimulated. The activities help to expand the reserve of brain cell connections and increase the chances of the brain functioning better and longer.

If health problems leading to the short-term memory loss have been going on for a short time, such as two to six months, fixing the health problems and leading a healthy lifestyle may return the memory function to normal levels. However, it may take several months for that recovery to occur. If the health problems have been going on for more than six months, fixing the health problems may improve short-term memory function but may not return it to the previous, normal level.

## Reading Suggestions

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# Chapter 3: A Full Medical Exam

By: Leilani Doty, PhD, Director, University of Florida Cognitive & Memory Disorder Clinics (MDC), Box 100236, McKnight Brain Institute, Gainesville, FL 32610-0236, Office 352-273-5550; Memory Disorder Clinic Appointments 352-294-5000. Partial support from Florida Department of Elder Affairs, Alzheimer's Disease Initiative. (2012)

## Purpose

To discuss the essential parts of a full medical exam with a physician who has special training and experience in dementia symptoms, such as problems with memory, language, decision-making, judgment, and other thinking functions.

## Objectives

Upon completion of this session, individuals will:

- Understand at least five signs of changes in memory, communication and thinking skills that indicate the need for a medical exam.
- Learn at least five important parts of a full medical exam for people with memory and thinking problems.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to ongoing decline over time. Though Alzheimer's disease is the most common progressive dementia, many other types of dementia exist.

## A Full Medical Exam

With more than 5.4 million people in the United States estimated to have Alzheimer's disease or a related dementia expected to reach more than 16 million or more people by 2050,<sup>1-4</sup> a full medical evaluation and treating any memory disorder early are key to maintaining self-sufficiency. Staying self-sufficient for as long as possible represents enormous savings of money, time, stress, and work for families.

The large numbers of fixable dementias and the different therapies available to help different progressive dementias emphasize the importance of undergoing a full medical exam by a physician with specialty training in the more than 200 fixable, treatable, and progressive dementias.

## Importance of Early Medical Exam

Currently, an estimated eight million people with Mild Cognitive Impairment live in the U.S.<sup>5, 6</sup> With the increased longevity of people, especially the retiring baby boomers, more cases of Mild Cognitive Impairment will surface. Many of these cases over time will progress to Alzheimer's disease or a related dementia. As a result family caregivers will deal with increased efforts to provide care and to cover costs. Thus, if memory decline can be evaluated and treated early enough, the decline may slow down, be reversed, or prevented. The resulting benefits to families and society will be enormous.<sup>7, 8</sup>

Research has found that some people with mild memory or other thinking difficulties who receive treatment can return to their normal functioning (normal for their age, education, and occupation levels) when evaluated six months, one year, or more later.<sup>6,9,10</sup> Reasons for the memory problems may have been due to low hormone levels, depression, high anxiety, fatigue, high amounts of stress, a mild infection that temporarily impaired memory, or some other health, environmental, or relationship conditions. When these health conditions were treated early enough, in many cases the memory ability returned.

## Preparing for the Evaluation

When symptoms, such as problems with memory, recalling specific words, losing objects at home, being unable to complete all the steps of a task, struggling to balance the checkbook, new difficulty using appliances, and getting lost in familiar neighborhoods first appear, an immediate medical evaluation with a doctor experienced in the diagnosis of dementia is important. Both the person

with the memory problem and at least one other individual who knows that person well should attend the clinical appointment for the medical evaluation.

Sometimes with permission from the person undergoing the evaluation, additional family members or friends attend the appointment. A discussion with the medical staff ahead of time can help to accommodate special needs, cultural differences, and the number of people who will come to the appointment. With permission from the person undergoing the medical exam and to help the family, a friend who is trained in health care should accompany the person with the disorder and the family caregiver (or significant other) to the appointment to provide additional needed details, to ask questions, and to hear as well as understand the medical recommendations. The trained person can take notes and explain later to the family the details of the evaluation and the plan of care.

In the absence of a trained person, some families successfully use a small tape recorder to capture details of the medical evaluation and discussion. Then they later can replay the tape to remind them of the discussion and recommendations from the medical visit.

For older people who have a memory disorder, the medical appointment should be the only scheduled activity for the day. This step helps avoid exhaustion and worry about making it to other events that are scheduled that same day.

### *A Medical Team Approach*

The medical evaluation at a group medical practice or university health center may involve a team of health professionals. A team of health specialists offers a range of skills such as in medical, psychological, and social services. At the end of the evaluation, a case conference should occur. The case conference should include the person undergoing the evaluation, at least one family member or significant other, and other appropriate people. The case conference should cover the health condition, the care plan with suggested treatments, follow-up services, and resources in the community to help the family.

During the case conference, it is important for the person with the memory disorder, the family caregiver (or significant other), and other loved ones who attend the meeting to be open about their questions and concerns. Before, during, and after the medical evaluation appoint-

ments, many questions may arise. Giving a copy of the list of questions and concerns to a member of the medical team such as a nurse or social worker beforehand helps in planning enough time for the case conference.

### *Parts of the Medical Evaluation*

A full medical exam by clinicians familiar with dementing illnesses is necessary to find the diagnosis and to recommend care. The important parts of a full evaluation include the following:

- A medical and surgical history of the person and any directly-related family members such as parents and siblings,
- A medical exam,
- A neurological exam,
- A psychiatric or psychological exam (including a screening for depression and anxiety), and
- A mental status exam [a neuropsychological evaluation of memory and cognitive (thinking) skills].

A full medical exam should consider details, such as the following:

- Current symptoms and changes in abilities to function;
- Timing of symptoms: which symptoms occurred first, second, third, etc.;
- Health history including past medical and surgical treatments;
- A review of all health problems;
- Social, education, employment/work/retirement history of the person with the symptoms;
- Health history of directly-related family, such as parents, grandparents, uncles, aunts, siblings, and children;
- History of uses/abuses (alcohol, tobacco, drugs, violence, etc.) and neglect;
- Brief questions about changes in driving or parking skills;
- Physical exam including blood pressure, weight, pulse, temperature, etc.;
- Specialty medical exams as needed, such as

neurology, cardiology, oncology, speech/physical/occupational rehabilitation, etc.;

- Psychosocial assessment;
- List of medicines (prescription and over-the-counter medicines, vitamins, herbs, etc.);
- Tests of small samples of blood and urine;
- Imaging such as MRI, CT, etc.; and
- Other tests as needed, such as breathing tests, stress test, EKG, EEG, EMG, chest x-ray, sleep study, spinal tap, etc.\*

\* *MRI – magnetic resonance imaging*

\* *CT – computer tomography imaging*

*EKG – electrocardiogram, a study of heart function*

*EEG – electroencephalogram, a study of brain function*

*EMG – electromyogram, a study of nerve function in the muscles*

### ***Possible Treatments and Recommendations***

Some treatments for Mild Cognitive Impairment may improve memory function and slow the rate of decline that is occurring. The complete medical evaluation may uncover a simple health problem that is easy to fix. For example, low levels of thyroid hormone, vitamin B12 or other B Vitamins may lead to problems with short-term memory and other functions of the body. Thyroid medicines or vitamin supplements can replace low levels to help restore health to the brain and the rest of the body.

The exam may reveal infections, issues dealing with pain, dehydration, poor sleep, and long-term stress. These are just a few of the many problems that interfere with good memory and thinking functions. Some medicines that help heart conditions, allergies, pain, or urine incontinence interfere with memory and thinking abilities.

The doctor may recommend a medicine. No clear, strong studies show that the medicines used to help people with Alzheimer's disease apply to people who have Mild Cognitive Impairment. Yet some physicians may recommend such medicines to see if they may help people with Mild Cognitive Impairment or other progressive dementias. These medicines include anticholinesterase medicines such as Aricept®, Exelon® or Razadyne® and protecting medicine such as Namenda®.

To determine if decline is ongoing and if safety is a concern, people with Mild Cognitive Impairment should undergo a medical check-up every six months or more often. If medical findings suggest an ongoing decline in memory and other thinking functions such as planning an activity or doing daily tasks, then the physician may recommend appropriate limits on these activities. One example is the area of driving, which is discussed in the later chapter “Driving & Progressive Dementia.”

## **Summary**

As soon as a problem occurs with memory, language, or other thinking functions, a full medical evaluation by a clinician skilled in the diagnosis of dementing illnesses should occur. The medical evaluation should include information about the symptoms, a medical and surgical history, a family health history, a medical exam, a neurological exam, a psychiatric or psychological exam, a mental status exam, questions about changes in driving, tests of blood and urine, an MRI or CT, and other tests as needed.

Medical recommendations should include treatment of any fixable health condition, healthier daily life habits, and routine health check-ups. The physician may recommend changes in current medicines or new medicines. Driving safety should be addressed with referrals for comprehensive driver evaluations when indicated. Further information is available at the following resources:

## **National Resources**

Alzheimer's Association 800-272-3900

[www.alz.org](http://www.alz.org)

ElderLocator 800-677-1116

[www.eldercare.gov](http://www.eldercare.gov)

***Florida Resources: Florida Department of Elder Affairs (DOEA)***

[www.elderaffairs.org](http://www.elderaffairs.org)

Florida Elder Helpline 800-963-5337

Florida DOEA 850-414-2000

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# Chapter 4: Firming up the Diagnosis

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## State of Florida Brain Bank

*By: Martha Purdy, MSW, LCSW, Brain Bank Program Supervisor, Alzheimer's and Dementia Resources Center, Inc., Orlando, FL, office; 407-843-1910 ext. 308; Alzheimer Disease Initiative (ADI) Advisory Committee Member, Chairperson of the ADI Brain Bank Subcommittee. Partial support from Florida Department of Elder Affairs, Alzheimer's Disease Initiative. (2012)*

### Purpose

To give an overview of the State of Florida Brain Bank program.

### Objectives

Upon completion of this session, individuals will:

- Understand three priorities of the State of Florida Brain Bank program.
- Discuss the application process for the State of Florida Brain Bank program.
- Identify at least two benefits of the State of Florida Brain Bank program to family members.

## Description of State of Florida Brain Bank

To help families of individuals with Alzheimer's disease and other progressive dementias, in 1987 the State of Florida expanded the Alzheimer's Disease Initiative (legislated in 1985) to include a State of Florida Brain Bank.<sup>1</sup>

The State of Florida Brain Bank program collects and studies the brains of deceased individuals who have been clinically diagnosed with a progressive dementia and compares their clinical diagnosis with the pathological diagnoses.<sup>2</sup>

In addition the Florida Brain Bank collects brains of normal, older, deceased persons who donate their brains in order for researchers to advance knowledge about the brain. Researchers study the normal brains and other brains to examine the tissue changes associated with normal aging in the hopes of finding some of the clues that will lead to answers about treating, curing, and preventing devastating dementia diseases.<sup>2, 3</sup>

Brain donation is a very generous act and is essential for providing brain tissue to learn and study the causes of various forms of dementia.

It is so important to study brain tissue as soon as possible after death before the tissue undergoes further misleading changes that people who sign up as participants in the Florida Brain Bank program, according to Florida law, must complete paperwork before the time of death. Only the next-of-kin of the brain donor can provide consent for an autopsy, once the donor is deceased. Therefore, the next-of-kin must complete all the necessary consent and medical forms before the time of death. This preparation before the time of death helps to avoid delays to the important autopsy procedures.

### State of Florida Brain Bank Program Goals

The following goals of the State of Florida Brain Bank program fall into two categories, Service Goals and Research Goals:

#### Service Goals

- Provides the means to obtain a brain autopsy and pathological diagnosis.
- Informs physicians about the accuracy of the initial diagnosis.
- Provides a diagnosis and closure to the family and the physician.
- Provides the Florida community opportunities to participate in research.
- Educates the Florida community about causes of dementia.

### *Research Goals*

- Provides brain tissue for researchers.
- Identifies symptoms leading to a more accurate diagnosis.
- Improves knowledge about the genetics of dementing diseases.
- Provides feedback about the accuracy of clinical diagnostic tools.
- Provides new targets for investigational drugs for dementing diseases and ultimately improves possible treatments.

## **History of Alzheimer's Disease Initiative State of Florida Brain Bank**

In 1987, when the State of Florida expanded the Alzheimer's Disease Initiative to include a brain bank, the Alzheimer's Disease Initiative (ADI) at that time was a program in the Florida Department of Health and Rehabilitative Services, Office of Aging and Adult Services.<sup>2-4</sup> Thus, the new State of Florida Brain Bank linked to the first four ADI Memory Disorder Clinics at the following locations:

- Mount Sinai Medical Center, Miami, Florida,
- University of Florida, Gainesville, Florida,
- University of Miami, Miami, Florida, and
- University of South Florida, Tampa, Florida.

The appointment of a Principal Investigator of the State of Florida Brain Bank went to Ranjan Duara, MD, the Medical Director of the Wien Center for Alzheimer's Disease at Mt. Sinai Medical Center, Miami Beach, Florida, who already had a program to recruit and study donors in Miami.<sup>1</sup>

As time passed, Florida Legislators continued to develop policy and services for the growing numbers of elderly in the state. During 1991 the Florida Statutes designated a new Department of Elder Affairs (Florida Statutes, Section 20.41 and Chapter 430). The Florida Department of Elder Affairs began operating in January 1992 and became the primary state agency for administering human service programs for the elderly. As a result, the Department of Elder Affairs assumed responsibilities for the growing

Alzheimer's Disease Initiative (ADI) program, which, of course, included the Brain Bank.<sup>1,4</sup>

### *Brain Bank Satellite Site in Orlando*

While serving as a member of the ADI Advisory Committee, Ranjan Duara, MD, met Patricia Goodwin Jimison, another member of the ADI Advisory Committee. Motivated to address the lack of local resources when she learned that her father-in-law was diagnosed with Alzheimer's disease, and then later when her husband, Jack, was diagnosed with the same disease, Patricia "Pat" Jimison had founded and was the first Executive Director of the Alzheimer Resource Center in Winter Park, Florida (now called the Alzheimer's and Dementia Resources Center based in Orlando).

Dr. Duara invited Pat Jimison to create a Florida Brain Bank in Orlando that would serve as a satellite site to the main office in Miami. Committed to the importance of providing caregivers with a definitive diagnosis of Alzheimer's disease and other dementias, Pat Jimison recruited Gary S. Pearl, MD, a neuropathologist based at the Orlando Regional Medical Center. Dr. Pearl donated his time to help Pat Jimison develop the Autopsy Only program for the greater central Florida area. In February 1988, the Autopsy Only program had its first official brain autopsy and since then has been one of the most active sites for recruiting, educating, and providing the highest quality reports regarding its donors.<sup>1,5</sup>

### *Other Satellite Sites in Florida*

Later Florida Brain Bank sites opened in Melbourne and Pensacola. Autopsies in the Tampa-Sarasota-Fort Myers area were covered by staff from the Medical Examiner's office in Tampa, Florida.

### *Participation of Highly Skilled Neuropathologists*

Through the years the neuropathology studies and diagnoses of the State of Florida Brain Bank have involved a series of topnotch neuropathologists, physicians with special training and expertise in evaluating the nervous system (the brain, the spinal cord, and the peripheral nerves): Michael D. Norenberg, MD, at the University of Miami Miller School of Medicine, William E. Ballinger, Jr., MD, at the University of Florida College of Medicine, Jocelyn H. Bruce-Gregorios, MD, at the University of Miami Miller School of Medicine, and, of course, Dr. Pearl at the Autopsy Only program in Orlando.

While at the Albert Einstein College of Medicine in New York, Dennis W. Dickson, MD, an internationally recognized expert on the pathology of Alzheimer's disease and related disorders, took over the State of Florida Brain Bank neuropathology evaluations in the early 1990s. After his move to Mayo Clinic, Jacksonville, in the late 1990s up to the current time, Dr. Dickson has been the neuropathologist and Medical Director of the State of Florida Brain Bank.<sup>1, 4, 5</sup>

### *State of Florida Brain Bank Research Priorities*

The State of Florida Brain Bank program has established the following research priorities:

- Find a cure.
- Develop simple, less invasive diagnostic tests.
- Find more advanced therapeutic interventions.
- Halt functional and intellectual decline.
- Provide as definitive a diagnosis as possible based on tissue examination as a service to families.
- With appropriate approvals, provide copies of the pathology report to the diagnosing and primary care physicians for their education.

The Florida Brain Bank Coordinators strive to do the following:

- Educate the public, caregivers, and professionals about the existence of the program;
- Enroll individuals with progressive dementia;
- Enroll older individuals without signs of dementia to serve as “controls”; and
- Provide the treating doctors and the participating families or designated significant other [the person(s) who hold the Durable Power of Attorney for Healthcare or serve as Guardian] with a final diagnostic report.

To fulfill the goal of strong scientific research, the State of Florida Brain Bank sites register people over the age of 18 if they have had a full diagnostic work-up from which they have received the diagnosis of Alzheimer's disease or a related dementia. This is the first requirement to be a State of Florida Brain Bank participant. The second re-

quirement is that the participants identify a (local) funeral home that they plan to use at the time of death.

## **Application Process**

### *Plan Ahead*

The application process to the State of Florida Brain Bank typically takes four to six weeks to complete, and the participant must be pre-registered at the time of death. When appropriate, the participant should be involved in the application process. Many people who appear to be aging normally and those with Mild Cognitive Impairment (MCI) who have participated in this process are very proud to donate their brains to science.

### *Application Form*

Application forms, which may be mailed to the donor or next-of-kin, must be completed and signed by the donor, if competent, or the donor's appointed legal representative, for example, someone holding the Durable Power of Attorney for Healthcare. The Florida Brain Bank Coordinator at each program site provides assistance. After the donor or the next-of-kin family member (or designated significant other) looks over and completes the application forms, the application packet goes back to the Brain Bank Program Coordinator for review. Next, a staff member will phone the family and go over that information.

One of the forms will be a Medical Records Release Form. Then using a copy of the Medical Records Release Form with a signature indicating Informed Consent, the staff member will write the physician(s) for the appropriate medical records. It is not the responsibility of the family to get the needed medical records.

### *The Medical Records*

What are the appropriate medical records? All records, beginning with the original neurological evaluation, pertaining to the medical evaluation and treatment of the neurodegenerative disease are necessary to paint a complete clinical picture of the participant. These medical records include evaluations and follow-up visits to a gerontologist, neurologist, neuropsychologist, and/or a neuropsychiatrist. The original neuro-diagnostic work-up must include a neurological evaluation, a list of special blood test results which may rule out many diseases that are reversible, and test reports such as an EEG (electroencephalogram) when appropriate. Also important are reports and copies of the

actual pictures, when possible, from brain imaging studies such as CT (CAT scan), MRI, PET, SPECT scan and other related brain scans.

### *Review of Application With Medical Records*

Once all of these medical records are received, the chart is sent to and reviewed by the chief neuropathologist who approves the entry of the participant into the program. When there is missing information and/or other concerns, the Florida Brain Bank Coordinator works to address these issues. As stated before, a person must be approved prior to death to be a part of this program.

## **Acceptance to the Program**

Once the applicant is approved, the Florida Brain Bank Coordinator phones the next-of-kin family member or significant other [the person(s) holding Durable Power of Attorney for Healthcare or serving as the Guardian] to inform them about being accepted. After the phone call, a letter of acceptance is mailed to the participating family (or designated legal representative). If the brain donor lives at home, a protocol (directions about how to proceed) for the time of death is included with the letter of acceptance. If the brain donor lives in a facility such as an ALF (Assisted Living Facility), Special Care Unit, nursing home, or related residence, the Director of Nurses receives the letter of acceptance with a protocol to be placed in the resident's medical chart. A copy of the Florida Brain Bank letter of acceptance and protocol also goes to the funeral home which the family has chosen.

### *Notifying the Florida Brain Bank Coordinator*

It is the family's responsibility to keep the Florida Brain Bank Coordinator up-to-date about any changes (such as changes in the residence, the funeral home, mailing address, etc.) and to provide medical records of any follow-up medical or dental visits that relate to the participant's neurological disease and/or decline.

The Florida Brain Bank Coordinator is available 24 hours, seven days a week. It is critical to call the Florida Brain Bank Coordinator immediately after the death has occurred and is pronounced. Once the family has had their time with the loved one, the Florida Brain Bank Coordinator will arrange with the funeral home contact person for the removal and transportation to the site of autopsy. The Florida Brain Bank Coordinator will also arrange for the medical team which will do the removal to arrive close

to the same time the body arrives. Remember, this is not a full body autopsy, only a brain autopsy.

Once the brain removal is completed, which is a 35 to 45 minute procedure, the next-of-kin family member (or designated legal representative) along with their funeral home contact person may proceed with their plans. It is important for the family to understand that the decision to have a brain autopsy will not interfere with any funeral or cremation arrangements they have made. The family may have an open casket funeral as there will be no disfigurement.

### *The Final Report*

A few months afterward, when the neuropathology study of the brain is completed, a written report is sent to the Florida Brain Bank Coordinator. This report is shared with the family after which they receive a written copy and are encouraged to contact the participant's treating physician to discuss the report further, if they wish.

With the permission of the family this report is sent also to the doctors who were treating the participant during the disease.

## **Reasons for a Brain Autopsy**

**Why have a brain autopsy?** This donation provides important brain tissue for researchers to study. Without such tissue there could be no research to study progressive dementias. The researchers work to uncover the chain of events that lead to the development and decline of progressive dementias. As mentioned previously, the Brain Bank Coordinator is on call 24/7. The reason for being available is so that the Brain Bank Coordinator can notify the appropriate people as quickly as possible. The tissue that is harvested as soon as possible after death still contains active molecules involved in the disease which provides a unique resource for researchers to study.

Countless research articles, abstracts, and symposia presentations have resulted from the State of Florida Brain Bank program. The tissue has been shared worldwide for international research studies. In October 2010, Dennis W. Dickson, MD, the State of Florida Brain Bank neuropathologist at Mayo Clinic, Jacksonville, had the honor of receiving a personal invitation to a White House briefing on Alzheimer's disease.

## Benefits to the Caregivers

**How does an autopsy benefit the family?** Some people realize that getting an accurate diagnosis gives the family important information about the medical history. Knowledge is power. It is important to remember that, yes, some types of dementia run in families but occurs in less than 1 percent of cases.

Other families want to contribute to the discovery of information that helps to lead to treatments, cures, or prevention of diseases. They believe that their donation will help to unlock doors for researchers. For many people, participation softens the helpless feelings of the caregiver and other relatives; the donation of the brain tissue gives them something positive to do for a disease about which little is known at this time (but the donation can help future generations). Some families receive a sense of relief when the neuropathological report comes and provides them with some closure to a long lasting series of challenges. There are so many other benefits that families have expressed – just a couple are mentioned next.

## Quotes of Appreciation

To describe the significance of the Florida Brain Bank program to caregivers, the following quotes from their letters may express their feelings best:

“Participating in the Brain Bank is the ONLY thing I felt I could do that might bring something positive from my family member’s suffering.”

“Thank you for giving my mother her last HOORAH, a gift to science, a gift to our future.”

## Summary

In summary, a participant in the State of Florida Brain Bank program must have had a full neurological work up, an application completed, medical records retrieved, and the whole package of information and materials in the chart reviewed and approved by the Chief Neuropathologist before death in order to be accepted into the State of Florida Brain Bank program. Upon death an autopsy is performed after which a neuropathology report is mailed to the family and treating physicians.

Donating to the State of Florida’s Brain Bank program is a perfect way for loved ones to leave behind an important legacy to their family and for scientific research. For further information contact:

- Martha Purdy, MSW, LCSW, ADI Brain Bank Program Supervisor, Alzheimer’s and Dementia Resource Center, Inc., 1506 Lake Highland Dr., Orlando, FL 32803; 407-843-1910 ext. 308
- Ranjan Duara, MD, Principal Investigator, or Yirah Ochoa, MHSA, Coordinator; ADI Brain Bank, The Wien Center, Mt. Sinai Medical Center, 4300 Alton Rd., Miami Beach, FL 33140; 305-674-2018 or 305-674-2543

## References

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# Chapter 5: Mild Cognitive Impairment (MCI)

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## **Purpose**

To give an overview of the signs, evaluation, and treatment of Mild Cognitive Impairment

## **Objectives**

Upon completion of this session, people will be able to do the following:

- Learn the signs of a possible Mild Cognitive Impairment.
- Learn about the difference between a possible Mild Cognitive Impairment and a progressive dementia such as Alzheimer's disease.
- Overview the clinical evaluation for possible Mild Cognitive Impairment.
- Learn at least five strategies to deal with a decline in thinking functions.

**Key Point** The key point is for older people to be aware of an early change in short-term memory or naming or other thinking function while they still are able to handle daily tasks and relationships. Such change(s) need a medical evaluation as soon as possible.

## **Mild Cognitive Impairment (MCI)**

As it is used here, the term Mild Cognitive Impairment (often shortened to MCI) refers to someone who has a mild decline in short-term memory, using words, or other thinking functions such as making decisions while still handling daily routines and responsibilities in their typical way. Essentially, they function quite independently with very little assistance or few reminders from others.

When people are very tired or worn-out, trying to handle too many tasks at once or stressed, they may have occasional difficulty with short-term memory. They may struggle while talking to recall a specific name of a person, place, or other detail. Or, there may be a small problem with another thinking function such as planning an office meeting or family event. Some call this occasional difficulty a “senior moment” or “brain jet-lag.”

If the memory loss or other problem is mild but noticeably different from typical behavior, a medical exam is important. The person experiencing the memory problem may be aware of the difficulty and/or someone else who knows the person well may notice it. Usually the person with Mild Cognitive Impairment is the first one to recognize the decline in memory, language, or other area of thinking. Sometimes, however, it is a family member or close friend who first realizes the change.

Some people with MCI may improve with medical treatment such as in cases when there is an inflammation, an infection such as a bladder infection, a vitamin B12 or other diet deficiency, or imbalance in hormones. In other cases, the MCI may remain at the same level without further decline.

However, in some people, the occasional problem may arise more often or become an ongoing issue. At first, with a short-term memory problem, the person occasionally may misplace things at the office or at home. There may be occasional, mild problems recalling words when speaking or planning a get-together with friends. However, though the change in function such as with short-term memory is noticeably different for that person, there are no additional problems. In other words, more problems with thinking functions, such as recalling words when speaking or writing, may not occur or may occur rarely.<sup>1-3</sup>

Some people with Mild Cognitive Impairment become worse over time when the short-term memory loss grows

and other thinking functions such as handling bills and preparing meals begin to become more difficult. Such change may be evidence of a progressive dementia such as Alzheimer's disease.

Mild Cognitive Impairment (MCI) is the diagnosis given to people who show primarily a mild short-term memory loss or mild decline in recalling words (or another thinking function) beyond what a medical exam should find for a person that age and educational or career background. At the same time the person can still function independently in daily life at their job, home duties, and relationships with very little help.<sup>1-3</sup>

Instead of using the general diagnosis of MCI, some doctors prefer to use more specific terms such as the following:

- *Amnesic* MCI indicating a mild decline only in short-term memory
- *Anomic* MCI indicating a mild decline only in the recall of words
- *Single-domain* MCI indicating only one area of decline such as memory
- *Multi-domain* MCI indicating more than one area of decline such as memory, recall of words, and planning events

### *Mild Cognitive Impairment: Signs*

- Problem primarily in one area of thinking such as short-term memory, naming, or other thinking function
- Medical testing shows mild decline in short-term memory, naming, or other thinking ability
- Abilities continue to manage normal daily activities, duties at work and home, and interactions. May need occasional help with some complicated or multi-step tasks.

## **Brain Cell Changes**

As stated before, in MCI, brain cell changes occur in one area of the brain that is responsible for a specific function. If brain cell changes expand to other areas of the brain and other functions decline, the ongoing decline may be a sign of a progressive dementia such as Alzheimer's disease or related disorders.

Early brain cell changes in the hippocampus can interfere with memory ability. The hippocampus is toward the front of the temporal lobes, an area of the brain located just above the ears. If the hippocampus cells are the only brain cells getting weak, then the decline may affect only short-term memory. However, over time the decline may spread to other areas of the brain and affect other functions such as language or using the hands in skilled ways such as zipping up a jacket.

If the brain cells in the language area of the brain (the top, rear area of the temporal lobes) undergo decline, then recall of words becomes difficult. Decline that is only in the language area may impact speaking as well as understanding words that others speak or reading words. The decline may include other abilities such as writing words. If the decline progresses to other areas of the brain, then other functions, such as memory, making decisions, or using one's hands in skillful ways, weaken. These changes may be signs that MCI has become a progressive dementia such as Alzheimer's disease or a related disorder.

In some cases MRI (magnetic resonance imaging) or CT (computer tomography) pictures of the actual brain may show a decrease in brain cells in the area of the brain that controls a specific function such as memory or in several areas that control several functions such as memory, word recall, and math skills.

### *Importance of Good Brain Function*

Short-term memory and thinking functions are important for keeping up with all the responsibilities, relationships, and activities in one's daily life. The short-term memory holds new facts and details, such as who, what, when, and where of a situation. Holding onto new information helps one remember an appointment or details of a conversation. Reading words on a sign directs you to the correct section of a store to find the items you need to buy. Adding or subtracting numbers is important for keeping track of money or the score of a game.

### *Importance of Early Medical Exam*

Currently, an estimated 8 million people in the U.S. have an MCI.<sup>4</sup> If early memory and thinking decline can be treated, slowed down, reversed, or prevented, the benefit to individuals, their families, and society will be greater than just cost savings. As a result people who receive early treatment are likely to experience better and longer brain health, independence, self-sufficiency, and quality of life.

Reasons for problems with short-term memory, language, or other thinking abilities may result from infections, pain, inflammations, depression, high anxiety, high amounts of stress, fatigue, or some other condition. Some research has found that after the treatment of these conditions, some people with mild memory or other thinking difficulties return to normal functioning when they undergo evaluations a year or more later.

Many people with MCI, despite their best and healthiest efforts, continue to decline slowly over a few years to a diagnosis of progressive dementia, such as Alzheimer's disease or a related dementia.

Some studies estimate that 10 percent to 15 percent of people with MCI will progress to Alzheimer's disease in one year. Other research suggests that changes to progressive dementia occur in three years or more. Researchers have found that up to 40 percent and even as many as 65 percent of people with MCI will progress to Alzheimer's disease or a related progressive dementia. This change over to Alzheimer's disease or a related dementia appears more likely in people with MCI who also have other mild problems with disorientation, anomia (difficulty recalling specific names or words), decision-making (or other executive functions such as planning or organizing events), or depression.<sup>4-9</sup>

## The Medical Evaluation

Medical appointments of older persons who have health problems such as pain, weakness, shortness of breath, heart problems, etc., should include a serious look at short-term memory and other thinking functions. A careful exam is necessary to identify all the conditions such as a vitamin deficiency or high blood pressure that may benefit from medical attention.

### *A Full Medical Exam*

A full medical exam should consider the following:

- Current symptoms & changes in abilities to function;
- Health history including past medical treatments, trauma (head injury), special diets, etc.;
- A review of all the problems the person is having (e.g., heart, vision, hearing, skin, gastrointestinal system, incontinence, sexual function, dental health, etc.);

- Social, education, employment/work/retirement history of the person with the symptoms;
- Health history of directly-related family, such as parents, grandparents, uncles, aunts, siblings, and children;
- History of substance uses and abuses (tobacco, alcohol, leisure drugs, etc.);
- Physical exam including blood pressure, weight, pulse (and sometimes temperature);
- Specialty medical exams when needed, such as neurology, cardiology, urology, oncology, speech/physical or occupational therapy, etc.
- Psychosocial assessment;
- List of prescribed and over-the-counter medicines (vitamins, herbs, etc.);
- Tests of small samples of blood & urine, imaging such as brain MRI, or CT, etc.;
- Other tests as indicated, such as breathing tests, stress test, EKG, EEG, EMG, chest x-ray, sleep study, spinal tap, etc.\*

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\* MRI – magnetic resonance imaging

CT – computer tomography imaging

EKG – electrocardiogram, a study of heart function

EEG – electroencephalogram, a study of brain function

EMG – electromyogram, a study of nerve function in the muscles

### *Medical Suggestions*

A careful medical evaluation may point to the need for a better diet or other lifestyle changes such as the following:

- Good nutrition: grains, fresh fruits, and vegetables every day.
- Ten to 12 glasses of water (or similar liquids) a day unless a physician limits liquids.
- Positive interactions.
- Physical exercise for at least 30 minutes at a time for at least five days a week.
- Daily brain exercise: crossword, jigsaw, and math puzzles; reading and talking about a story; music; handcrafts; planning and doing tasks; etc.

- Daily purposeful (useful and meaningful) tasks and fun activities.
- Time with others and time alone.
- Reduced stress.
- Adherence to your physician's and dentist's advice to take care of your health!

The doctor may recommend a change from a medicine such as an allergy medicine or incontinence medicine that blocks memory function to a medicine that treats the problem without weakening memory function. Some recommendations for therapy for a diagnosis of Mild Cognitive Impairment include applying medicines that act to boost memory and thinking functions.

Based on the results of the medical evaluation, some physicians may prescribe a medicine such as Aricept®, Exelon®, or Razadyne®, which may help memory function or Namenda® which may offer protection. Though these medicines are approved by the FDA (Food and Drug Administration) to help people with Alzheimer's disease and related dementias, some physicians may suggest that people with MCI try these medicines for possible help.

To determine if decline is ongoing and if safety is a concern, people with MCI should undergo regular medical check-ups. At this time, certain medical tests such as neuropsychological tests to evaluate changes in memory and other thinking functions are covered once a year by Medicare.

If medical findings suggest an ongoing decline in memory, in other thinking functions such as planning an activity involving several details and steps, and in other learned skills such as how to use tools, then the physician may recommend appropriate limits on these activities.

### *Mild Cognitive Impairment (MCI) and Driving*<sup>10, 11</sup>

At the point of beginning decline, the person with MCI probably still is fully safe as a driver of motor vehicles such as cars, golf carts, motor boats, or rider mowers. However, early planning should consider choices for future transportation when changes may occur in the ability to drive safely. As people live longer, many of them outlive their ability to be safe drivers. These changes mean that people should plan for other sources of regular transportation to get to the grocery store, appointments, other programs, and visits with family and friends.

Any reports from the person or the family (or significant other) that driver safety is a concern should come to the attention of the physician or other health professional, who is following up the general health care of the person. Reports from the person undergoing the medical exam or the family about scrapes in parking lots, crashes, traffic citations, aggressive or impulsive driving, or avoiding certain traffic situations, roads, settings, etc., suggest an increased risk for unsafe driving.

Such situations should be discussed with the physician or health professional who may recommend that the person take a comprehensive driver evaluation (test) before continuing to drive. Often a driver refresher course, training with a driver safety specialist to update skills, or adding features to the car, such as a wider rear-view mirror or larger side-view mirrors, may eliminate driving risks.

Note that the following: a comprehensive (full) driver evaluation is more extensive than the regular driver test at a Department of Motor Vehicles and Highway Safety. The comprehensive driver evaluation test involves different vision tests, tests of memory and cognitive functions, a test of movement and strength, and an on-the-road test. Instead of an on-the-road test, some places use a virtual test, an indoor set-up that was designed to imitate on-the-road driving situations.

A driver safety specialist who is certified in comprehensive driver evaluation is trained in assessment and may offer some "driver rehab." Some of these specialists are occupational therapists; others have different training.

## **Planning Ahead**

Besides early intervention to stop or slow down memory and cognitive decline, another value of early medical evaluation is the ability to plan ahead of time for future lifestyle adjustments. Early on, assistance from experts in retirement planning may help people establish priorities, and plan steps to fulfill dreams such as the following:

- Traveling,
- Taking educational workshops or courses,
- Writing down stories describing the history of the family,
- Learning a new hobby such as refinishing worn out furniture, or
- Improving skills to perform better at a favorite sport.

Early planning should consider legal, financial, and possible needs for the long term, such as skilled health care preferences, especially in the event of a health crisis. The planning should consider housing alternatives as preferences and abilities change; for example, some communities-for-a-lifetime offer limited assistance while others offer a full continuum of services.

The costs of housing alternatives may range from reasonable to expensive. The choices for long-term housing should consider the flexibility of contracts and the ability to change a residence without losing large “binders” or “down payments,” which can lead to financial losses.<sup>12</sup>

Other issues to consider are accessing resources for the family (or significant others) to provide leisure activities, life enrichment classes, and increased assistance with homemaker services or personal care over the long term.

## **Tips for Dealing With Mild Cognitive Impairment (MCI)**

Persons with MCI and their family caregivers should try to learn about and work within the range of the strengths of the person with MCI. The next section overviews various memory aids and other strategies that can help with the mild changes that occur in memory and other thinking functions.

### *Tips for Mild Decline in Short-term Memory*

Persons with mild short-term memory loss should try to work within the range of their memory ability. Knowing that one’s memory works better after a good night’s rest, after the second cup of coffee/tea, or when one reviews the next day’s schedule the night before, may help a person remain high-functioning.

The ability to remember may be better during the early morning or mid-morning and much worse when the person is tired at the end of the day. If the short-term memory is less reliable after a day of back-to-back appointments, any appointments that involve careful thinking, remembering many details, and important decisions should occur at the beginning of the day while the person is fresh. More specifically, financial or legal discussions and other important decisions should occur when the person is rested, clear-thinking, and alert.<sup>12</sup>

Persons with MCI should keep organized and clutter-free. As much as possible, they should stay on routine for tasks and schedules.

### *Tips for Mild Decline in Recall of Words*

Whether during a formal or a casual lunch, before meeting with others, it should help to review the names of people one will see and important points to discuss. Reviewing the details of an agenda of a meeting and writing down important points or questions to consider can help keep names and specific words available in case one’s recall gets shaky. At meetings that start with introductions, some people find it helpful to jot down the names of people in a seating-chart format that shows where the person is seated, her/his company and job title and role at the meeting.

### *Tips for Those With Mild Decline in Planning or Making Decisions*

When planning or making decisions, it may help to start with a list of all the tasks to do and all the points to consider. Then looking at the list, one can set up priorities, such as what needs to be handled first, second, and third. Another approach is to set up what should be done today, what can wait till the following day, and what can wait till much later. Remember, some tasks are not worth doing at all.

It is important to focus on one task at a time and one step at a time. Thus, pick one task, identify the steps, think about the first step, and then focus on doing the first step. After the first step is done, go on to the next step. Some people like to check off each step as it is done. When the task is done, check it off and go on to the next task. As the tasks are done, keep that list in a notebook or electronic device for later reference (in case you wonder whether the task was ever done).

Work with at least one other trusted person when making difficult or important decisions such as whether to sell a car, make a legal decision, or move to a new place. Write down the choices with advantages and disadvantages for each choice. Mark a plus sign (+) for each advantage or a minus sign (-) for each disadvantage to see quickly the best choice (the one with the longest list of advantages or the most + signs, of course).

## *General TIPS to Help the Person With MCI*

- Use reminder notes, a calendar, an appointment device or other tool. Keep reminder notes together in one place. Stick to routine schedules.
- Keep paper and pen/pencil handy. When you think about it, write it down. Write down the following: ideas, passing thoughts, tasks to do, people to call, etc. Keep handy names and phone numbers of people who can help.
- Work at paying attention. Watch, listen, focus, keep eye contact.
- Repeat information out loud and a few times quietly to yourself.
- Do one task at a time, one step at a time, the usual way.
- Go the way you know. Keep handy simple directions with large print (and a small, simple map) to different places and the easiest way back home again.

Sometimes when there are two best choices, it may be worthwhile to try out the first choice for a few days and then the second choice for a few days to see which works better.

## **Assisting Other People Who Have MCI**

The family of the person with MCI can help by keeping the schedule simple and routine, planning activities well enough ahead of time, allowing extra time for tasks or appointments, making the home, work, or leisure setting easy for daily functions, and scheduling in down-time as rest periods in between varied activities.

### *Tips for People Who Assist Those With MCI*

- Keep activities simple, one step at a time. Set rest times for each of you.
- Discuss details briefly and use the actual names of people, pets, places, etc. Use specifics and repeat the details.
- Encourage; do not push nor nag. Do tasks together and one step at a time.
- Repeat the question, request, or answer in a pleasant tone or voice.

- Allow enough time for tasks and appointments.
- Act as a team to pay bills, do yard work, or wash the dog.
- Hang a large calendar. Keep the daily schedule handy and follow it. Schedule daily tasks, activities, and exercise at routine times. Mark off what is done and past appointments. Keep that page for later reference.
- Post a sign or picture to note special activities.
- Encourage fun, daily brain exercise: puzzles, cards, chess, checkers, computer games, books, etc.

It is helpful for the family members or significant others to stay as positive as possible. Being pleasant, patient, and sensitive to preferences in providing assistance helps the person with a MCI to maintain a sense of being the following:

- Valued,
- Self-sufficient,
- Independent, and
- An important contributor to the activities in the workplace and at home.<sup>12</sup>

It is important for the person with MCI to have daily brain stimulation and to keep up to date with the news, family events, upcoming birthdays, and holidays. Interesting discussions with family and friends could cover the following:

- Special events - local art fairs, exhibits, or sales;
- Community and world news – elections, the Olympics;
- T.V. and radio shows – sports, music, comedy; and
- Family activities and visitors (practice their names before they arrive).

## **Summary**

When a person experiences mild occasional changes in memory, speech, planning, or other thinking ability that may be noticed by family members or significant others, a medical evaluation as soon as possible is important. The physician may uncover fixable causes of the decline and

provide recommendations such as changing medicine, giving thyroid replacement medicine, or treating an infection. These medical treatments may fix the problem or improve memory and thinking functions.

The medical evaluation may result in a diagnosis of Mild Cognitive Impairment (MCI) which typically indicates that there is reduced short-term memory ability, language, or other thinking ability, but otherwise the person is functioning well at normal levels with a minimum of help. Healthful changes in lifestyle such as good nutrition, drinking plenty of water every day, regular physical exercise, daily brain exercise, and reducing stress may lead to better memory function or may help to avoid further decline in memory.

While some people remain at the MCI level, others who have MCI go on to develop further decline such as Alzheimer's disease or a related disorder. Careful medical monitoring, developing ways to deal with the memory problems and other thinking problems, and planning ahead for lifestyle changes will help people deal most effectively with care management over the long term. Further information is available at national and Florida programs:

## National Resources

Alzheimer's Association: 800-272-3900,  
[www.alz.org](http://www.alz.org)

ElderLocator: 800-677-1116,  
[www.eldercare.gov](http://www.eldercare.gov)

AAA Foundation for Traffic Safety Senior Driver:  
[www.seniordrivers.org](http://www.seniordrivers.org)

AARP Driver Safety:  
[www.aarp.org/families/driver\\_safety](http://www.aarp.org/families/driver_safety)

National Highway Traffic Safety Administration:  
800-327-4236 [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

### **Florida Resources: Florida Department of Elder Affairs (DOEA)**

Florida Elder Helpline: 800-963-5337

Florida DOEA: 850-414-2000,  
[www.elderaffairs.org](http://www.elderaffairs.org)

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# Chapter 6: Fixable Memory Disorders (Fixable Dementias)

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## *Purpose*

To discuss the signs of memory, language, and other thinking problems that may be fixable memory disorders (also called fixable dementias).

## *Objectives*

Upon completion of this session, individuals will:

- Understand at least five changes in memory, communication, and thinking skills that indicate the need for a medical exam.
- Learn at least five causes of potentially fixable memory disorders.
- Learn at least five recommendations to address decline in memory and thinking function that result from fixable causes.

***Key Point*** The key point is to be aware of changes in memory or thinking abilities and to have these changes clinically evaluated as soon as possible by a physician with specialty training and experience in Alzheimer's disease and related disorders.

## **Early Memory & Thinking Changes**

Early changes in one or more brain functions such as memory, language, or thinking skills may begin to show up as often misplacing items or difficulty keeping up during a conversation with friends. Especially in a large group of people with many activities occurring at the same time, the person with short-term memory problems and some difficulty with language skills may struggle to understand the flow of topics or to answer a simple question. In a different example, at a restaurant, the person may struggle to select an item from a menu or figure out and add the tip to the bill. Or, the first sign may be starting many tasks and not finishing any.

A teacher with new thinking (cognition) problems may lecture easily on old material but struggle to explain the recently published research findings on the topic or to answer unexpected questions from students.

At the end of a long trip, the driver who has memory and organization difficulties may struggle to remember a road sign with directions to follow a new detour due to major road repairs.

## *Early Signs of Memory Decline*

People who notice occasional struggles to remember details may be experiencing a change in memory ability. Some examples of memory problems include the following:

- Forgetting the time of an appointment;
- Forgetting whether a task was done already, such as paying the same bill twice;
- Forgetting the location of keys, eyeglasses, wallet, favorite slippers, magazine, etc.; and
- Forgetting the credit card after a store purchase.

## *Early Signs of Language Decline*

An early sign of language difficulty may show up as struggling to recall names or specific words. Some examples include the following:

- Not recalling the name of a favorite fruit or the city where someone was born and grew up;
- Not understanding others;
- Using a related but wrong word when speaking or writing; and

- Mixing up letters in a word when speaking or writing.

### *Early Signs of General Thinking Decline*

An early sign of a problem with thinking may involve the following:

- Difficulty planning,
- Difficulty making decisions or choices, and
- Difficulty carrying out all the steps to a task.

### *Noticing a Change*

The important point is noting the change (or changes) from the person's usual ability to remember, communicate, or think carefully. The change in ability may be noticed by the person who is having the difficulty. Or, instead, the change may be noticed only by a loved one who lives with the person and not the person with the disorder. Sometimes it is the family member who lives at a distance and who visits every few months who notices the change.

## **Full Medical Check-Up As Soon As Possible<sup>1-4</sup>**

Any notice of change in memory or thinking should result in a medical exam as soon as possible by a physician who is an expert in the dementias. The doctor may find a problem that is easy to fix. The physician or other health provider may identify a health condition that is manageable enough to slow down ongoing decline such as changes in the brain from poor blood flow due to irregular heartbeats.

Even if the changes represent a progressive condition such as Alzheimer's disease, uncovering the possible diagnosis early on may help to preserve memory and thinking skills for a longer period of time. This is the approach of: "A stitch in time saves nine." In other words, early help may prevent the need for major medical treatments later.

### *Signs of Mild Memory or Thinking Changes*

- Difficulty remembering appointments
- Difficulty recalling the names of friends, neighbors, and family members
- Unable to keep up with a group discussion
- Difficulty recalling whether a task was just completed the day before

- Difficulty planning and carrying out plans such as for a party
- Difficulty choosing, such as which coat or shoes to wear
- Different behavior: restless, quick to get angry, withdrawn, untidy, poor grooming, etc.
- Loss of interest in meeting with friends or doing activities
- Struggling with work or home tasks that used to be routine and easy; needing help or hints about the next step in a task

### *Importance of Short-term Memory and Thinking*

Short-term memory and thinking functions are important for keeping up with all the responsibilities, relationships, and activities in one's daily life. Short-term memory is important to hold onto new information, such as who, what, when, and where of an event. It is important to remember information about current activities such as what you just did, to know what comes next, to move on to the next steps, and to stop when a task is done. The task could be preparing a meal or dressing. Language skills are important for relationships whether with a family member, business partner, or grocery clerk.

### *Importance of Early Medical Exam*

An estimated eight million people in the U.S. have Mild Cognitive Impairment (a mild decline in short-term memory or recall of words with few or no other thinking difficulties). An estimated 5.4 million people have Alzheimer's disease or related disorder. Treating a memory disorder early is essential.<sup>1-4</sup>

An early medical evaluation of memory or thinking abilities by a doctor with expertise in Alzheimer's disease and related disorders may lead to finding a fixable health condition and the person gaining healthy memory or thinking skills. The doctor may be able to slow down the ongoing decline with recommendations, such as treating blood pressure or heart problems. The doctor may recommend changes in lifestyle such as the following:

- A better diet;
- Drinking 10 to 12 glasses of water a day;
- Sleep hygiene (general suggestions to improve sleep);

- Reducing negative stress; and
- Increasing physical and brain exercise.

### *Reasons for the memory problems may result from:*

- Poor diet;
- Dehydration (not drinking enough liquid every day);
- Poor vision or hearing;
- Medicines that interfere with memory function;
- Depression;
- High anxiety;
- Stress;
- A mild infection that temporarily impairs memory;
- Fatigue;
- Poor sleep or loss of sleep over several days or longer; and
- A general acute health problem such as the flu or a chronic health problem such as pain (back pain, arthritis pain, headaches, etc.).

Treating these conditions and reducing unpleasant stress may help the memory and thinking skills return to normal levels of functioning.

With medical help some people may still have short-term memory difficulties but have no further decline. Other people despite their best and healthiest efforts may convert over time to slow, progressive declines in memory and other thinking functions. However, good medical care may slow down the progressive decline.

Slowing down, reversing, or preventing the loss of memory, language, or other thinking functions benefit the patient, the family and society. The person with the health condition will remain self-sufficient longer. In addition, the family will delay the challenges and tasks of full caregiving and benefit from savings in caregiver energy, time, and money.

## **A Full Medical Exam**

An early full medical exam by a doctor with special training and expertise in progressive dementias should include

a summary of the first signs of problems with memory, language, or other thinking abilities. The summary should note which problem was first, which one was second, etc., and when they occurred, such as in the morning, evening, in a large group, etc. The history of “problem events” should also contain the person’s medical and surgical history. In addition, the health history of directly-related family members such as parents and siblings offers important information.

The full clinical exam covers:

- A medical exam;
- A neurological exam;
- A psychological exam (including a screening for depression and anxiety);
- A mental status exam [a neuropsychological evaluation of cognitive (thinking skills) and memory functions];
- A list of medicines, vitamins, minerals, herbs, and other supplements taken daily and occasionally; and
- Use of alcoholic liquids and tobacco

The doctors also need results from completed tests, such as blood and urine tests, and MRI (Magnetic Resonance Imaging) or CT (Computer Tomography) pictures of the brain.

### *Fixable Health Problems*

A complete medical evaluation may uncover a simple health problem that can contribute to memory problems and is easy to fix such as:

- Low levels of thyroid hormone;
- Low levels of Vitamin B12 or other B vitamins such as niacin, folate, etc.;
- Infections;
- Pain;
- Dehydration and poor diet;
- Poor sleep;
- Long-term stress;
- Depression; and
- Medicines that interfere with memory and

other thinking functions (Some medicines important for heart conditions, allergies, pain, or urine incontinence may interfere with memory function.)

Thyroid medicines or vitamin supplements can replace low levels of these substances to help restore health to the brain and rest of the body. If the health problems leading to the short-term memory loss have been going on for a short time, such as two to six months, fixing the health problems may return the memory function to normal levels. However, it may take several months for that recovery to occur. If the health problems have been going on for more than six months, fixing the health problems may improve short-term memory function but may not return it to the previous, normal level.

### *Healthy Lifestyle*

With a healthy lifestyle many people may be able to improve memory and other thinking functions, maintain the current level of function, or slow down progressive decline. A healthy lifestyle includes good nutrition, especially grains, fresh fruits and vegetables, drinking 10 to 12 glasses of water a day unless a physician limits liquid intake. Regular physical exercise for at least 30 minutes (five days a week) is very important for the health of the body and especially for the brain.

Also important to brain health is daily brain exercise such as the following:

- Doing crossword and jigsaw puzzles; art or crafts; playing or listening to music; joining a book discussion group;
- Reading and discussing the reading material;
- Visiting with friends;
- Doing meaningful activities that give a sense of purpose such as volunteering or gardening; and
- Trying to learn something new every day.

Doing a routine activity such as brushing one's hair or teeth a different way by using the opposite hand stimulates brain cells. (More information on brain exercise is available in the Chapter on Daily Health: Tips.)

- Good nutrition: grains, fresh fruits, and vegetables every day.

- Ten to 12 glasses of water a day unless a physician limits liquids.
- Regular physical exercise for 30 minutes at a time at least five days a week.
- Daily brain exercise: crossword and jigsaw puzzles, art and crafts, etc.
- Time with friends and time alone.

### *Medical Follow-Up*

The physician may recommend a medicine to improve memory function and to slow the rate of decline. The group of medicines that appear to help memory function (anticholinesterase medicines) are as follows: Aricept®, Exelon® or Razadyne®. The physician may also recommend the medicine, Namenda® that appears to protect neurons.

To determine if the memory, language, and other thinking functions have been fixed, stay fixed, or begin to decline, people who have undergone treatment should have a regular medical check-up. Some physicians recommend return visits every three months, six months, or longer.

If medical findings suggest a continuing problem with memory or other thinking functions, the physician may recommend other therapies for maintaining or improving skills. In some cases, the physician may set limits on some activities to address safety such as not using sharp or complicated tools and not driving any kind of motor vehicle.

### **Summary**

Whenever a person suspects changes in memory or thinking ability, a medical evaluation should occur as soon as possible by a physician who has specialty training and experience in Alzheimer's disease and related disorders. The physician may uncover fixable causes of the decline in memory and may recommend changes. The changes may include treating an infection, a thyroid or vitamin deficiency, or changing a medicine that interferes with memory and other thinking abilities. Such treatments may lead to improved memory and thinking. If caught early enough, treatment may return full memory functioning. If the problem has gone on for too long, treatment may be only effective enough to stop further decline.

Healthful changes in lifestyle such as good nutrition, drinking plenty of water every day, regular physical exercise, daily brain exercise, and reducing stress may lead to better memory function or may help to avoid further decline in memory. The following list includes some basic national and Florida-wide sources that provide more general information:

## National Resources

Alzheimer's Association: 800-272-3900,  
[www.alz.org](http://www.alz.org)

Eldercare Locator: 800-677-1116,  
[www.eldercare.gov](http://www.eldercare.gov)

### *Florida Department of Elder Affairs (DOEA)*

Florida DOEA: 850-414-2000

Florida Elder Helpline: 800-963-5337  
[www.elderaffairs.org/](http://www.elderaffairs.org/)

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# Chapter 7: Alzheimer's Disease Overview

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## Purpose

To describe the basic symptoms of Alzheimer's disease and the decline as the disease progresses.

## Objectives

Upon completion of this session, individuals will do the following:

- Understand the early symptoms of Alzheimer's disease.
- Recognize the three stages of Alzheimer's disease.
- Learn about treatment approaches for Alzheimer's disease.
- Learn about some behaviors that challenge caregiving.

## Dementia

Dementia is the decline of memory and other mental abilities while the person is awake and alert to the point of interfering in the ability to do daily tasks or interact well with others.

Dementia is not a normal part of aging. It may result from a one-time event such as a small stroke or periodic strokes that lead to a vascular dementia. Or, the dementia slowly may get worse over time such as with Alzheimer's disease.

## Numbers of People Affected

The number of Americans with Alzheimer's disease has more than doubled since 1980. It is estimated that now about 5.4 million people in the United States have Al-

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

zheimer's disease or a related dementia. The numbers of people with Alzheimer's disease (or a related disorder) are predicted to climb as high as 16 million by 2050. The most common form of progressive dementia, Alzheimer's disease is the sixth leading cause of death in the U.S., but fifth in the death of people 65 and older.<sup>1</sup>

In Florida, about 524,000 people have Alzheimer's disease or a related memory disorder. Those numbers are expected to grow also as the older population increases and lives longer.<sup>1</sup>

Alzheimer's disease occurs in both sexes, all races, and in people of every social, economic, and environmental background.

## Risk Factors for Alzheimer's Disease<sup>1-4</sup>

Many risk factors can lead to a greater chance of developing Alzheimer's disease. Some of the factors that appear to increase the risk of developing Alzheimer's disease include the following:

- Older age;
- A strong family history of Alzheimer's disease;
- Serious head injury such as from a sports injury or auto accident;
- Chronic infections;
- A lack of formal or informal education (and, thus, lack of brain stimulation, also called "brain exercise"); and
- An unhealthy lifestyle (such as poor nutrition and alcohol abuse).

Other risk factors that impact the healthy flow of blood throughout the brain such as diabetes, blood pressure problems, or irregular heart beat increase the risk for another kind of dementia, vascular dementia (sometimes called cardiovascular dementia). Sometimes vascular dementia occurs along with Alzheimer's disease. People with a diagnosis of vascular dementia who follow their doctor's recommendations to control conditions that impact the heart and blood circulation may be able to slow down the decline in this kind of dementia.

It is not certain why older people over the age of 65 have a higher incidence of Alzheimer's disease. Also, it is not clear why almost 50 percent of people over age 85 are likely to develop the disease.

Some medical tests can indicate an increased risk to develop Alzheimer's disease. Family genes appear to play a stronger role in people who develop Alzheimer's disease as young adults, in their 20s, 30s or 40s. Increased risk is associated with family genes such as in the amyloid precursor protein (APP) gene, in the presenilin 1 (PSEN1) gene, and in the presenilin 2 (PSEN2) gene.

An increased risk also appears to relate to an inherited form of a complicated protein (the apolipoprotein) which is on Chromosome 19. (Each cell in a person normally holds 46 chromosomes which are actually 23 pairs of chromosomes. One chromosome comes from each parent to form each pair). Thus, one copy of the different apolipoprotein (usually called APOE) genes comes from each parent. A simple blood test will show the type of APOE that a person has inherited. Blood test results that show two copies of the apolipoprotein E4 gene (commonly called the APOE-4 gene) indicate a higher risk of developing Alzheimer's disease.

Some genetic tests are currently available to identify specific conditions; for example a blood test can test for the diagnosis of Huntington's disease. However, researchers are still working to identify biomarkers for Alzheimer's disease. A biomarker is a substance to identify some change or special condition or disease in the body. Biomarkers must be simple, safe, inexpensive, accurate, and reliable for use on humans. Thus far, no current tests meet all these criteria for a biomarker to accurately identify Alzheimer's disease. Researchers are working hard on tests of spinal fluid and tests involving imaging studies such as PET and SPECT scans to find a useful test that meets all the necessary criteria to diagnose Alzheimer's disease or a related dementia.

## Alzheimer's Disease<sup>1-4</sup>

Alzheimer's disease is a slowly progressive disease process that affects brain cells and may last two to 30 years. Early brain cell changes may occur 20 to 40 years before a person or family member notices the first signs of decline. The disease results in an ongoing loss of memory, communication skills, and other thinking abilities with a gradual decline in being able to do tasks or self-care. Alzheimer's disease is not normal to aging, not contagious, and not caused by aluminum pots or pans.

### *Changes in Brain Cells*

The adult brain holds about 100 billion neurons, each neuron with 7,000 to 10,000 branches (dendrites). The dendrites connect the brain cells to each other through 100,000 synapses. Alzheimer's disease seems to result from changes in the neurons and the synapses.

Researchers think that abnormal clumps (amyloid plaques around the neurons in the brain) and twisted strands of abnormal tau protein fibers (neurofibrillary tangles within the neurons of the brain) are involved in the decline of Alzheimer's disease. In addition, reduced amounts of neurotransmitters (the chemicals that carry messages from neuron to neuron) such as acetylcholine in the synapses (the gaps between neurons) may be strong factors that contribute to the decline.

A loss of neurons throughout the brain may show up in pictures of the brain from an MRI (magnetic resonance imaging) or a CT (computer tomography). The loss of neurons shows up in the MRI or CT pictures as dark spaces and less brain tissue in that area of the brain. As the brain tissue decreases, brain fluid fills the space that is left.

Also, as the brain tissue decreases, the cell functions, which depended upon those brain cells, decline and disappear. For example, the shrinking of the hippocampus cells (anterior temporal lobe) will result in a short-term memory decline. A shrinking of the front section of the brain (the frontal lobes) will match the decline in decision-making, planning and ability to do daily tasks or self-care.

### *Overview of Signs of Alzheimer's Disease*

The signs of Alzheimer's disease usually show up at first as short-term memory loss and difficulty recalling and using specific names of people or objects when talking. Other early symptoms may include communication prob-

lems such as understanding what others are saying especially in a group of people and difficulty with skilled hand movements such as working with power tools or using a cell phone.

Later, there may be problems with getting lost in a familiar neighborhood, using eating utensils, following directions to a new store, making choices, using appropriate judgment, restlessness or the opposite (a lack of interest or energy), and mood swings. Many years later as the disease progresses with continued decline of memory and thinking skills, the caregiver serves as the memory system and provides nearly complete or full care for the daily needs of the person with Alzheimer's disease.

The signs and progress of Alzheimer's disease differ from person to person. The differences relate to which brain cells are shrinking and how fast the change occurs. Other reasons for differences may involve people's general health, lifestyle, personality, education, genes, cultural background, occupation, and environment.

### *Importance of Medical Evaluation and Diagnosis by a Medical Expert*

Problems with short-term memory, language, etc., may result from many health conditions including Alzheimer's disease. Some of these other conditions such as dehydration, infection, poor diet, and hormone imbalance are treatable. With medical treatment of the conditions, if the problems have not been ignored too long, in most cases, the memory and other thinking problems return to normal.

Some other conditions such as high blood pressure, diabetes, or unsteady heart beat may be managed better by carefully following the doctor's recommendations regarding healthy diet, exercise, and medicines. The better management may improve memory ability and other thinking skills or, at the very least, slow down the decline.

It is critical for anyone having problems with memory, communication, etc., to have a full medical check-up as soon as possible. A series of medical tests including blood tests must occur to narrow down the cause of the memory problem. A cure may be possible or at the very least some therapy may improve health, memory, other thinking functions, and long-term care management.

A full medical check-up should include the following:

- A medical and neurological evaluation to identify an illness or infection causing signs of progressive dementia;
- A neuropsychological evaluation to identify strengths and weaknesses in specific areas of thinking such as memory, language, following directions, making choices, switching from one step to another, etc.;
- A psychiatric evaluation to rule out depression, anxiety, stress, or other conditions that may interfere with normal function;
- Tests including many blood and urine studies, pictures of brain tissue through CT (computer tomography) or MRI (magnetic resonance imaging) or SPECT (single positron emission computerized tomography); and
- When needed, other tests, such as an EEG (electroencephalogram), a chest x-ray; heart studies such as EKG (electrocardiogram), halter monitor, echo sonogram, or a sleep study.

These tests rule out treatable causes of the memory and thinking difficulties and lead the doctor to provide the best "educated guess" about the health condition and treatment suggestions. Though scientists still do not understand the cause, treatment, and prevention of Alzheimer's disease, a full medical work-up may identify health concerns which are contributing to the decline. In addition, the doctor may recommend therapies to improve brain functioning and brain health.

### *Treatment for Alzheimer's Disease*

Though no cure exists yet for Alzheimer's disease, some medicines are available to help memory and other thinking functions. The medicines that boost the level of acetylcholine in the synapses (the gaps between neurons across which the messages travel) appear to boost memory and other thinking functions in some people. Also, they appear to slow down decline for a couple of years or more.

These "memory booster" medicines (called anti-cholinesterase medicines) include donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®, formerly known as Reminyl®). A different medicine, memantine (Namenda®), seems to offer some protection for the neurons and doctors may prescribe it along with one of the earlier "memory booster" medicines. Doctors

may prescribe other medicines to help control behavioral symptoms such as depression, anxiety, sleeplessness, agitation, and wandering.

## Stages of Alzheimer's Disease

Alzheimer's disease may be described as having an early, middle, and late stage. The rate at which a person moves through the stages is unpredictable and may take anywhere from two to 30 years. The stages often overlap.

### *Stage 1: Early Stage of Alzheimer's Disease*

The Early Stage of Alzheimer's disease may appear very slowly at first and gradually become more evident. It may last from two to 10 years. The person may or may not be aware of having difficulties. An excuse such as fatigue, extra stress, stubbornness, or laziness may be blamed for the problems.

Early problems may include the following:

- Struggles with short-term memory;
- Difficulty recalling and saying specific names or words;
- Organizing a big meeting;
- Adding new information to a lecture or talk that has been given a few times before; or
- Adding up numbers such as when balancing a checkbook.

With mild short-term memory problems, the person may be able to handle motor vehicles well. Any reports of changes in driver skills should be discussed during the medical evaluation, especially difficulty parking, minor car scrapes, maneuvering in traffic, accidents, or a "near miss."

The problems may become serious enough at this stage to interfere with doing jobs that carry a great deal of responsibility such as working as a bank teller, store manager, news journalist, or a grandparent caring for young children.

Typically, reminder notes, calculators, alarm watches/clocks, or a good executive secretary can keep the forgetful person on task and on time. A routine schedule and routine ways of doing tasks can be helpful.

### *Stage 2: Middle Stage of Alzheimer's Disease*

The Middle Stage of Alzheimer's disease may last four to six years. The decline becomes more evident to the person, family, and friends. In some cases, the person with the decline may not be aware of the decline; this lack of self-awareness (called anosognosia) is a sign that there is some brain cell loss in the front part of the neocortex (known as the frontal lobes).

In this stage, there is more difficulty with the following:

- Short-term memory;
- Talking in complete sentences;
- Understanding long responses or explanations from others; and
- Doing a series of different tasks or completing a multi-step task.

Actions that involve several steps such as picking one's own clothes from the closet and getting dressed become more difficult. Planning, cooking, and serving a meal become difficult although the person may work well when teaming up with someone else who gives hints about the next step needed. Abilities may change from one day to the next or from one hour to the next.

After having a good night's sleep, being fresh during the morning may result in the person functioning better. Being tired at the end of the day may result in less ability to function.

The person in the Middle Stage of Alzheimer's disease may be left alone for an hour or so at a time if someone checks on them occasionally from a distance or close up. In the home setting, a caregiver who is away from home for a couple of hours should make a phone call or have a relative or neighbor available to check the person, especially in case immediate help is needed.

Sometime in this stage, the person should undergo a comprehensive driving evaluation or stop driving. (Note that a comprehensive driving evaluation tests more areas of function than the simpler driving test of the Department of Highway Safety and Motor Vehicles.)

### *Stage 3: Severe Stage of Alzheimer's Disease*

The Severe Stage of Alzheimer's disease may last from one to five years. Typically people are unable to do the following:

- Remember for more than one or two seconds;
- Understand words;
- Express more than one word at a time or use meaningful language; and
- Know how to use an object such as a comb or fork.

They typically need complete assistance 24/7. They may not recognize close family members, but have a sense of familiarity (knowing that the person who smiles at them is someone who links to them or cares for them every day). Usually during the final months or days of life, the person with progressive dementia is unable to walk and may be unable to swallow.

Changes in the nervous system may appear through simple reflex actions, such as the following:

- Startle reflex to a loud noise;
- Sucking reflex to a straw placed near the mouth;
- Strong, tight hand-grasp reflex to someone's extended hand;
- Difficulty letting go of the other person's hand; or
- Quick look at anyone who moves or talks near the person.

The most common illness that leads to death is an infection such as a bladder infection or pneumonia.

The person in the Severe Stage of Alzheimer's disease is oriented to the current moment and is totally dependent on others for care and survival. They respond well to:

- Caregiver smiles;
- Pleasant, soft background music;
- Gentle touch when providing care; and
- Offers of liquid and smooth foods (such as applesauce, custard, or pureed soups).

The family caregiver must provide constant help and supervision with all (activities of daily living) personal care activities such as eating, drinking, mobility, bathing, dressing, and toileting. Thus, it is absolutely essential for family caregivers as well as other caregivers to schedule in regular respite for themselves.

### **Summary**

Alzheimer's disease affects about 5.4 million people in the United States and more than half a million people who live in the State of Florida. Alzheimer's disease affects women and men, people of all races and people throughout the world. Risks for the onset of Alzheimer's disease in young adults under 60 years of age include a strong family history. For older people over the age of 65, some of the possible risks include a history of head injury, a lack of "brain exercise," an unhealthy lifestyle such as poor nutrition and a lack of physical exercise, alcohol or tobacco abuse, and chronic infections.

It is critical to undergo a full medical exam as soon as problems with memory or thinking show up. The medical exam should be done by a physician with specialty training and experience in dealing with Alzheimer's disease and related disorders. A medical exam may uncover fixable health problems or treatments to slow down the decline of mental functions.

A slowly progressive disease that may last from two to 20 or more years, Alzheimer's disease may be described in terms of three stages. In Stage One of Alzheimer's disease, there are difficulties with short-term memory, recalling and using specific, correct words when talking, and clumsiness with hand skills. In Stage Two of Alzheimer's disease, memory and communication gets worse. Also, the person may need help with routine tasks such as meal preparation, laundry, dressing, and paying bills. This may be the time to stop driving any motor vehicles. In Stage Three of Alzheimer's disease, the person may be able to remember for no more than a few seconds and may need full-time help 24/7 with routine personal care tasks such as dressing, walking, or using the bathroom. The demands on the family caregiver are taxing, and regular respite for the caregiver is essential at this point.

## Recommended Reading

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# Chapter 8: Comparing: Alzheimer's Disease, Cardiovascular Dementia, & Lewy Body Dementia

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## **Purpose**

To overview and compare three different categories of progressive dementias:

- Alzheimer's disease
- Cardiovascular dementias
- Lewy body dementia

## **Objectives**

Upon completion of this session, individuals will:

- Have learned the signs of Alzheimer's disease, cardiovascular dementias, and Lewy body dementia.
- Have learned about the medical evaluation and treatments for Alzheimer's disease, cardiovascular dementias, and Lewy body dementia.
- Have learned about the care management of Alzheimer's disease, cardiovascular dementias, and Lewy body dementia.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

## **Introduction**

Alzheimer's disease is the most common progressive dementia affecting more than 5.4 million people in the United States and more than 523,000 in Florida. Many researchers think that cardiovascular dementia is the second most commonly occurring type of dementia while other researchers think that Lewy body dementia (also called Lewy body disease) is the second most common progressive dementia. Some of the differences in these three types of progressive dementias are described briefly below.

## **Alzheimer's Disease**

Alzheimer's disease typically starts with short-term memory loss and difficulty recalling specific words (or names of people or objects). Sometimes an early sign is clumsy hand skills such as new difficulty using one's hands (such as using a wrench, a crochet hook, or a hair dryer). As time passes, some confusion about time and place may occur, followed by problems making decisions and completing tasks at work or home. Typically symptoms appear in people over age 60.

At first the memory problems may include forgetting specific facts or details such as an appointment with the barber or events from the day before. The person with the problem may struggle to recall the names of people or places such as the names of people at a family reunion.

### ***Early Alzheimer's Disease: Mild Decline in the Following:***

- Short term memory
- Knowing date and place (current location)

- Recall of words
- Understanding what others say
- Skilled hand movements
- Organizing major events
- Decisions and judgment
- Focus
- Awareness of changes in abilities

As the decline continues, the person may forget to pass on an important phone message. During conversations, the individual may mispronounce words or use the wrong word. Hand skills learned years ago such as fixing a flat tire, sewing a hem, hanging a picture on the wall, or brushing one's teeth may become difficult.

### *Middle Stage Alzheimer's Disease:*

#### *More Decline in the Following:*

- Short term memory
- Knowing date and place (current location)
- Recall of words or using correct words when talking
- Understanding spoken or written words
- Decisions and judgment
- Ability to do tasks with many steps
- Ability to understand incoming information (what is seen, heard, smelled, tasted, touched, etc.)
- Adaptability to changes

Hand skills may be clumsy or tools may be used incorrectly such as using a knife to eat potatoes and gravy or using a toothbrush upside down. As time goes by, it may become difficult to choose which shoes to wear, the steps to do yard work, or which item of clothing to put on first (underwear goes on first). The person may become more irritable and restless, or the opposite, more quiet and withdrawn.

Usually a person with Alzheimer's disease maintains general movement and balance abilities such as those used when walking or swimming until later in the course of the disease.

During the late, severe stage of the disease, memory may only last only two or three seconds or none at all. Prescription medicines are available to boost memory and thinking functions and thus enable some abilities to function for a longer period of time.

### *Severe Alzheimer's Disease:*

- Few communication skills, little understanding or speech
- Does some one-step tasks or unable to do any tasks
- Less or little control of movement or balance
- Few social graces; more spontaneous outbursts
- Behavioral problems, such as wandering, getting lost; not willing to bathe, change clothes, or stop current activity; not willing to start a task or activity
- Incontinent
- Unable to walk, unable to sit for long; bedridden

## **Cardiovascular Dementia**

Cardiovascular dementia is considered the second most commonly occurring dementia in the U.S. A cardiovascular dementia often shows up when there is a health history of heart or blood circulation problems. Heart conditions may involve heart valve problems or the heart rate being too fast, too slow, or irregular. Blood circulation problems may result from the following:

- High blood pressure,
- Too high bad cholesterol (LDL) or triglycerides; too low good cholesterol (HDL),
- Arteriosclerosis (thickening and hardening of the arteries) or atherosclerosis (a type of hardening of the arteries due to build up of fatty deposits in the arteries),
- Unstable or long-term diabetes (Type 1 Diabetes) which can lead to changes in blood vessel walls, or
- Several tiny strokes or a stroke that involves brain cells that control specific thinking functions.

These conditions interfere with good blood flow to important areas of the brain responsible for different memory, thinking, and movement functions. Often the family can pinpoint when the change(s) in function occurred. For example, the family may describe that “everything was fine” but “something changed” when...:

- He awoke from a nap,
- We were leaving a family gathering to go home,  
or
- She was in the middle of a conversation, etc.

The family may describe different times when functioning changed, each time getting a bit worse in a step-by-step decline. Sometimes the family describes a specific time of decline, after which the person improved and remained stable for a period (sometimes long period) of time, but then something else happened leading to sudden decline.

These steps of decline (called stepwise progression) often cluster around other medical issues, such as a heart attack, a hospitalization, or major surgery involving anesthesia. In some cases with isolated events of change, the family may report that since the event causing the decline, over the past year there has been slow, steady improvement.

At first a stepwise decline may affect general thinking such as the ability to focus, plan, and use good judgment. Usually memory and speech decline later unless changes in blood flow affect specific brain cells that handle short-term memory and/or the ability to recall words. The person may act disoriented to time and place, inattentive, and answer questions with general or vague responses. There may be personality changes such as becoming more irritable, more passive, depressed, or more ups and downs in mood. These behaviors plus a health history that involves problems with heart function and blood circulation indicate a strong possibility of cardiovascular dementia.

## Lewy Body Dementia (LBD)

While many researchers think that cardiovascular dementia is the second most commonly occurring dementia in the U.S., recently scientists have insisted that Lewy body dementia (LBD) is the second most commonly occurring progressive dementia. Perhaps LBD is the third most common progressive dementia. Often called Lewy body disease, LBD may be hard to identify. The ups and downs of changes in symptoms (some days the person seems clear-thinking and at other times foggy-thinking) often

make the diagnosis hard to narrow down. Sometimes family members think the person is being lazy, uncooperative, or stubborn because of the unpredictable up and down changes.

The symptoms of LBD may appear in younger adults, people in their late 40s or in their 50s. Typically, the early symptoms of LBD include a mixture of four classic signs:

- Occasional visual hallucinations,
- Movement difficulties (such as stiffness in walking or difficulty getting into or out of a chair),
- Personality changes (becoming more withdrawn or, the opposite, more outgoing than is normal for the person), and
- Difficulties with changing attention, alertness, memory, and thinking skills (sometimes called clear versus cloudy thinking), such as understanding, talking, and planning activities.

### *Visual Hallucinations*

Early on, there may be visual hallucinations (seeing people or objects that are not real, but are imaginary). Sometimes, there are auditory hallucinations (hearing people, music, or sounds that are not there and that others do not hear). Some people who have these problems are aware that the people or animals they see are not really there. Often the people who see the images are comfortable with them while the family members may be upset.

**CAUTION: In people with LBD, antipsychotic medicine to treat the hallucinations and make them stop or to treat sleep problems may lead to extreme behaviors, opposite to the expected result. Sometimes the antipsychotic medicines add to the decline in thinking and movement ability, which may not improve as much as expected when the medicine is stopped.**

### *Movement Changes*

An early sign of LBD may be some stiffness when moving or clumsiness such as when going up or down stairs. As time goes on, the person with LBD moves more slowly with stiffness although there may be times when movement is easier and other times when the person seems to “freeze-up.” After a while, the person will develop clumsy hand movements when doing tasks such as struggling to do the following:

- Put on a belt when dressing;
- Use the phone, stove, or microwave; or
- Set the alarm clock.

The difficulty with movement of LBD may be confused with symptoms of Parkinson's disease. While the person (and a caregiver) is at the medical office, the physician may do a one-time, brief trial of a Parkinson's medicine (a dopaminergic medicine). The trial involves a few steps. First the physician will do a medical exam of movement and thinking abilities, next recommend the person take a small dose of the Parkinson's medicine, and stay in the waiting room for 45 to 60 minutes, after which the physician will repeat the medical exam. An improvement in movement and thinking function indicates Parkinson's disease or Parkinsonism (signs of changes indicating a condition that is a cousin of Parkinson's disease but not actually Parkinson's disease). No improvement from the dopaminergic medicine strengthens the suspicion of LBD. Some people with Parkinsonism signs may benefit from a dopaminergic medicine while others do not; thus, it is critical that the physician base a recommendation of such medicine upon a medical exam.

As LBD continues, skilled movements and general body movements become more difficult and may lead to the person's need for help with all tasks, even personal ones such as bathing or feeding.

### *Personality Changes*

The family usually notices a change in personality that at first may occur occasionally and then more often as time passes. Some examples of personality change include: quicker to anger, more withdrawn, no longer interested in leisure activities that were formerly enjoyable, not willing to do routine tasks, or refusing to keep up with personal hygiene and care.

### *Memory Changes*

People with LBD usually experience visual hallucinations and movement problems before there are problems with short-term memory. Then later, other thinking difficulties occur such as decision-making, planning, considering consequences before acting, or completing tasks.

### *Clear and Cloudy Thinking*

They may complain about feeling as if their brain has an on-off light switch that is unpredictable. Sometimes they

feel clear-headed and then suddenly their brain seems foggy, sluggish, or empty. Often the description of the symptoms indicates the need for an EEG to identify seizures that may be occurring.

Some people with LBD are partially aware or unaware; they wonder why family members complain about problems that do not seem to exist. Family members who observe the changes may be unsure about what is happening and may assume that the changes result from problems at work, being over-tired, being "under the weather," uncooperative, or being stubborn.

### *Sleep Difficulties*

Sometimes an early sign is a REM-sleep disorder. Rapid Eye Movement sleep is an early stage in the healthy sleep cycle. REM-sleep disorders may include body movements such as strong kicking, arm swinging, and loud yelling. These movements usually are the result of the person acting out a dream while asleep. Typically, the sleeping person is not aware of the activity.

## **Medical Exam & Treatments for Progressive Dementias**

In general, for any sign of a progressive dementia, people who have changes in memory, speaking, other thinking skills, movement, or being unable to keep up with daily tasks and routines, should undergo a full medical evaluation by a doctor who is a specialist in evaluating, diagnosing, and treating progressive dementias. A full medical evaluation may uncover a fixable problem such as low blood levels of thyroid hormones, vitamin B12, or other important measures of healthy body function. The medical evaluation can narrow down the type of progressive dementia so that treatments can improve function and not make disabilities worse.

The medical evaluation may uncover medicines (prescribed or over-the-counter), special foods, or natural supplements or supposed "miracle cures" that interfere with memory and thinking functions, increase sleepiness, interfere with balance, or increase the risk of falling. Such medicines include the antihistamines (such as cough or allergy medicines), some sleep medicines, some medicines for bladder control, and some pain medicines.

### *General Medical Suggestions*

The physician and health team members also may recom-

mend lifestyle changes and other therapies. The physician may offer medicines to stabilize the health problems, reduce the rate of decline, and help memory function. For example, recommendations may include regular physical exercise, brain exercise, social activities, proper liquid intake, and good nutrition.

### *General Suggestions for Caregivers*

Caregivers should remember that keeping a sense of humor active every day is important. The caregiver should also try to do the following:

- Be consistent. Do things the same way each time. Stay on a daily routine.
- Stay positive and use positive body language: words of praise, smiles, pleasant voice, gentle movements, and contact.
- Take your time; one step at a time.
- Make eye contact to get the person's attention. Use simple words, point, or act out to give directions.
- Keep pleasant distracters handy: snacks, music, a pet, a photo.
- Let others help: family, friends, colleagues, other staff, and community resources.

To help a person who has less ability to use their hands to do skilled tasks:

- Use familiar actions and tools which are easier than anything new.
- Do one step at a time. Use one tool or one object at a time.
- Avoid sharp or dangerous tools.
- Move slowly, no rushed or fast movements.
- Proximal movements (movements toward the body) are easier than distal movements (movements away from the body).
- As each step is completed, use simple words to remind about the next step (if needed).

### *Suggestions for People With Alzheimer's Disease*

Alzheimer's disease affects two people (at least), the person with the diagnosis and the family (significant other) care-

giver. Usually the caregiver is a woman (typically the wife and/or adult daughter), who provides care.

#### *Early Alzheimer's Disease: Forgetfulness*

In the first stage, Forgetfulness, the person usually functions pretty well with reminders. Reminders may include a note, a calendar, a timer that buzzes, a reminder phone call, or a friendly reminding word from a family member, neighbor or friend. With reminders the person may be nearly self-sufficient in activities on the job, at home, and with personal care. The physician may recommend a "memory medicine" and highlight the importance of a healthy lifestyle, especially physical and brain exercise.

#### *Middle Stage Alzheimer's Disease: Confusion*

In the second stage, Confusion, the person may need occasional assistance. Someone else should be readily available to help when needed. If the helper is at work or shopping and out of the home, the helper should be available by phone. The helper may assist with complex tasks such as choosing and setting out clothing to wear for an outing, setting up some dinner on a plate with a spoon, or getting out the garden tools for yard work. The physician may recommend a "memory medicine," a medicine to offer protection to brain cells, and highlight the importance of a healthy lifestyle, especially physical and brain exercise and activities during the day.

#### *Severe Alzheimer's Disease*

In the third stage, Severe Dementia, the person needs constant assistance and supervision and should be in a protective setting at home or in a facility. The place of residence needs to be safe with good lighting, smooth floors to avoid falls, and grab rails to ease walking and general movement, especially in the bathroom, kitchen, outside porch, and stairway. Over time the person with dementia may not recognize family members, not remember that they just ate dinner, and thus may ask about food or keep going to the refrigerator. Chewing and swallowing may become difficult. Later, they may be unable to talk or walk, but still will enjoy pleasant music, a gentle backrub, or a positive, relaxed visit from a loved one. The physician may highlight the importance of a healthy lifestyle, physical therapy and exercise, a routine of daily activities, and respite for the caregiver.

### *Suggestions for People With Cardiovascular Dementia*

For a cardiovascular problem, the physician may recommend a new therapy such as a pacemaker or medicine to

stabilize the heart beat. The physician will likely recommend changes in diet, more physical exercise, lower levels of stress, ways to lower blood pressure, diet changes or/and medicine to decrease the bad cholesterol (LDL), and diet changes to increase the good cholesterol (HDL). Changes in lifestyle may improve the control of diabetes. People with cardiovascular dementia will benefit from a daily schedule of interesting activities. To distract a person before they begin a negative mood or anger outburst, the caregiver should maintain a positive setting and keep handy positive, funny short stories especially about family members or close friends, interesting topics to discuss, sayings, music, songs, a different activity to start, and pictures, especially family photos.

### *Suggestions for People With Lewy Body Dementia*

Often people with LBD who have movement difficulties may benefit from physical therapy evaluations for gait training, balance exercises, and suggestions of appropriate daily exercises. Occupational therapists may offer ways at home to increase safety and make it easier to use the kitchen, bathroom, bedroom, eating utensils, clothing (without zippers or buttons), etc.

When hallucinations seem pleasant and safe, no treatment is advised. Educating the family helps them to accept the situation. Changes to help people cope with frightening or threatening hallucinations include increased lighting in the house, calming talk or music, or covering mirrors or other shiny surfaces. The physician may offer other suggestions to deal with “unsafe” situations.

People with LBD should avoid taking any antipsychotics. They should undergo a brief trial to see if a medicine used for Parkinson’s disease may help them to move or think better; it may or may not help. Serotonergic medicines, usually prescribed for people with depression, often help people with LBD.

## **Planning Ahead**

Whenever someone receives a diagnosis of a progressive dementia, education about the condition and planning for the future should occur as soon as possible. The education and planning should involve the person who has the disease, the family, and close friends who may be able to help in different ways, especially as care needs increase over time. Caregivers should think ahead and be ready to adapt to changes in their loved one at the first signs of

further decline and disability. The home and routines should always be safe, simple, interesting, and pleasant.

The Checklist on Family Matters (found on page 59) is a guide to help with planning. Planning ahead should involve long-term management issues that involve making decisions about preferences, the health of all family members, financial and legal planning, transportation alternatives, and safety issues.

Also important are planning ahead to develop back-up systems. There may be changes in weather resulting in power outages, being homebound several days, or requiring evacuations. Accidents involving the person with the diagnosis, the caregiver, or both may require temporary hospital care, leaving no one at home to feed pets or pay bills.

The following lists some national and Florida resources that offer information and referrals to services on the national and local levels to help families plan ahead.

### *General National Resources*

Eldercare Locator: 800-677-1116;  
[www.eldercare.gov](http://www.eldercare.gov)

### *National Resources for Alzheimer’s Disease*

Alzheimer’s Association, Inc.:  
800-272-3900; [www.alz.org](http://www.alz.org)

Alzheimer’s Disease Education & Referral Center (ADEAR): 800-438-4380; [www.nia.nih.gov/Alzheimers/AlzheimersInformation/AboutUs.htm](http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/AboutUs.htm)

Alzheimer’s Foundation of America:  
866-232-8484; [www.alzfdn.org](http://www.alzfdn.org)

### *National Resources for Cardiovascular Dementia*

American Heart Association:  
[www.americanheart.org/](http://www.americanheart.org/)

American Stroke Association:  
[www.strokeassociation.org](http://www.strokeassociation.org);  
[www.helpguide.org](http://www.helpguide.org)

National Stroke Association:  
[www.stroke.org/](http://www.stroke.org/)

# CHECKLIST ON FAMILY MATTERS

The following checklist should help to organize family matters and plan ahead.

## LEGAL MATTERS

Contact attorney or financial expert about:

- Money Planning
- Durable power of attorney (DPA), DPA, Springing DPA (give date to start)
- Living will; health surrogate; full code; pre-hospital DNR (Do Not Resuscitate)
- Trust funds
- Legal changes due to moving to another state or change in caregiver(s)
- Guardianship (Plan ahead to avoid the need for guardianship.)

## FAMILY BUSINESS

Someone must handle:

Regular bills:

- Electric/gas    Rent/mortgage    Water/sewer
- Car    Phone    Pet care
- Television/cable
- Back-up plans. If something happens (hurricane, fire, etc.), what is the family back-up plan? Who helps? List items to toss into a box or suitcase quickly before an emergency evacuation, such as: important papers, medicines, clothing, incontinence garments, water, food, etc.
- Enroll with driver license/ID 2 emergency contact people @ [www.hsmv.state.fl.us/](http://www.hsmv.state.fl.us/)
- Wallet-size page: brief Health Record: allergies, major illness, surgery, medicines, etc.; I.C.E (In Case of Emergency) number on cell phone with health information & contacts
- Medicine (Dose? Where is medicine located?)
- Help with grocery shopping, bills, cooking, cleaning, laundry, house repairs, yard, and travel
- Real estate (Location of property and deeds? Co-owners?)
- Money matters/bank & other money accounts (Location? Keys? Co-signer?)

- Checking, savings, money market, fund beater, IRA, CD
- Safety deposit box; safe (Keys or combination to open?)
- Social Security or pension (if under age 66, Social Security Disability):
- Check, mailed home or direct deposit
- Change the representative payee?

## INSURANCE

Know policy schedule, location and agent. CHECK WAIVERS!!

- House    Life Insurance    General Medical
- Car    Veterans medical    Medicare
- Theft    Disability    Medicaid

## Safety

Safety-proof the home. Plan ahead for crises: remove firearms; lock up sharp knives, tools, etc.

- Drivers must be safe! Plan ahead for other transportation. Silver Alert (sheriff office) for missing drivers.
- Identity bracelet/necklace for wanderers; locks on doors, fenced yard, recent photo on file Medic-Alert/ Safe Return Program); patient-caregiver bracelet set available; Life Line; ICE (In Case of Emergency) medical summary & contact information card (1-877-564-6423 toll free)
- FL ABUSE Registry Hotline (abuse, neglect, threat/ exploitation) 1-800-962-2873/1-800-96-ABUSE

## IN EVENT OF DEATH

- Summary of assets
- Funeral & memorial service details
- Autopsy for diagnosis
- Cemetery lot (Deed? Location?)

*Doty, L. Univ. of FL Memory Disorder Clinic (352)273-5550, Bx 100236, Gainesville, FL 32610-0236. Partial funding: FL Dept. of Elder Affairs, Alzheimer's Disease Initiative. Adapted from Alzheimer's Resource Center, Pat Jimison & Shellie Brassler, Orlando, FL. (2012 edition)*

## *National Resources for Lewy Body Dementia*

Lewy Body Dementia Association:  
800-LEWYSOS or 800-539-9767;  
[www.lewybodydementia.org](http://www.lewybodydementia.org)

Lewy Body Disease:  
[www.helpguide.org/elder/lewy\\_body\\_disease.htm](http://www.helpguide.org/elder/lewy_body_disease.htm)

## *Florida Resources: Florida Department of Elder Affairs (DOEA)*

Florida DOEA: 850-414-2000;  
[www.elderaffairs.org](http://www.elderaffairs.org)

Florida Elder Helpline: 800-963-5337;  
800-955-8771 TDD; 800-955-8770 (Voice)

## **Summary**

While Alzheimer's disease, cardiovascular dementias, and Lewy body dementia (LBD) are the three most common progressive dementias in the United States, there are overlaps and differences in the signs of the diseases, the treatments, and the care management.

*Alzheimer's disease* typically begins with decreased memory, difficulty recalling words, and difficulty with complicated tasks. The slow decline may occur over many years, even before signs are noticeable. After a full medical exam, a physician may recommend changes in lifestyle and medicines to help memory and thinking skills.

*Cardiovascular dementias* typically occur with sudden decrease in function. Sometimes there is slow change with a sudden decline over a few hours, days, or weeks. The difficulties with thinking, communication skills, mood, and personality changes usually reflect the areas of the brain where cells responsible for these functions suffer from changes in circulation.

Sometimes the decline appears to stay at the same level for quite a while or, in some cases, abilities may slowly improve. An evaluation by a physician who has special training and expertise in progressive dementias is critical because medical recommendations to treat heart and circulation problems may stabilize or significantly slow down the rate of decline.

*Lewy body dementia (LBD)* typically carries early signs of visual hallucinations. Though the person with LBD sees hallucinations, usually the person is aware that the hallucinations are not real. Of note, antipsychotics should not be prescribed to deal with hallucinations in people with LBD. Also early on, clumsy or stiff movements such as when walking are evident. Family may report that the person with the condition shows occasional signs of losing focus or losing the train of thought. Later, memory or other thinking problems surface on a regular basis.

Again, an evaluation and diagnosis by a physician with expertise in the many types of treatable and progressive dementias is critical. A full medical evaluation must occur before medical recommendations for treatment of the dementia and general health management. Some of these recommendations may include physical therapy, occupational therapy, sleep hygiene, good water intake, a nutritious diet, and interesting, meaningful activities every day.

## *Planning Ahead*

Whenever someone receives a diagnosis of a progressive dementia, as soon as possible the family should learn about the health condition and plan for the future, especially for back-up plans in case of emergencies. *A Checklist on Family Matters* provides a guide to help with planning. Information about programs and resources that may help the family over the long term should be included with the planning information.

# Chapter 9: Intellectual and Developmental Disability (i.e., Down Syndrome) & Alzheimer's Disease

By: Leilani Doty, PhD, Thomas J. Buckley, EdD, Matthew P. Janicki, PhD, Shelly Greenberg, RN, H. Murray Todd, MD, Kathleen J. Houseweart, MBA, & Carol W. Waters, PhD (2016)

## *Purpose*

To improve specialized person/family-centered health services and community resources to enhance the quality of life for people with lifelong intellectual and developmental disabilities (IDD), such as Down syndrome, who have Alzheimer's disease or a related dementia.

## *Objectives*

Upon completion of this session, people will be able to do the following:

- Know at least five early typical signs that suggest progressive dementia and occur more commonly than memory and language problems in people with lifelong intellectual and developmental disability (IDD), such as Down syndrome.
- Identify at least five points of a full clinical evaluation.
- Understand at least three strategies for care management to optimize functioning of people with IDD, such as Down syndrome, who develop Alzheimer's disease or a related dementia.

- Learn about the Florida Model: Addressing Dementias, a state plan which includes specialized, comprehensive, dementia-capable services and supports for people with IDD, such as Down syndrome, and Alzheimer's disease or a related dementia.
- Access at least three sources of information and resources which educate caregivers and provide services to families in order to promote quality in daily life for people with IDD, such as Down syndrome, and Alzheimer's disease or a related dementia.

**Key Point** The key point is to understand that people with lifelong intellectual and developmental disabilities (IDD), e.g., Down syndrome, typically have different early signs of Alzheimer's disease or a related dementia (ADRD), may be at greater risk, have onset at a younger age (during young or middle-age adult years), decline at a faster rate, and benefit greatly from special services and supports to the family.<sup>1-5</sup>

## *Some Terms Used in This Chapter*

**Lifelong** means throughout life.

**Intellectual and developmental disabilities (IDD)** refer to genetic and acquired (such as from head injuries, illness, etc.) difficulties that involve memory and thinking skills as well as physical functioning and may include decreased social interactions.<sup>1-5</sup>

**Developmental Disability (DD):** The U.S. Federal Developmental Disabilities Act defines DD as a lifelong condition that impairs normal development and a mental and/or physical impairment occurring before age 22 that results in substantial limits to function in three or more major activities including the following:

- self care;
- receptive (i.e., understanding) and expressive (i.e., speech, writing) language;
- learning;
- movement such as walking;
- self direction;

- capacity for independent living and economic self-sufficiency; or
- requires special and individualized services over the lifespan.

States may vary in this definition; Florida uses categorical conditions in its definition:

*Florida Statute, Chapter 393* defines developmental disabilities as a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

**Intellectual Disability (ID)** may be described as follows:

- Has below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy that is not a mental illness or psychiatric impairment;
- Varies in degree and co-impairment; and
- Is compensated by training, education, remediation, habilitation, and supports for life activities.

Examples of IDD: Down syndrome, fetal alcohol syndrome, fragile X, infection or malnutrition of the mother, environmental toxins (i.e., mercury, lead).

**Down syndrome** is the IDD that is the focus of this chapter. Down syndrome results during development before birth. Each person with Down syndrome is a unique individual. No matter which of three forms of Down syndrome a person has, some of the following characteristics to different degrees or none at all may occur:

- Standard trisomy 2 – Extra copy of chromosome 21; accounts for approximately 95 percent of Down syndrome
- Translocation – Piece of chromosome 21 ‘translocates’ to another chromosome (usually chromosome 14); accounts for approximately 4 percent of Down syndrome
- Mosaicism – Mixture of cells in that some cells contain 46 chromosomes and some contain 47; accounts for approximately 1 percent of Down syndrome (generally with fewer of Down syndrome traits though this varies)

- » Characteristic facial features, upward slant to the eyes;
- » Low muscle tone, small stature;
- » Intellectual and physical delays;
- » Higher risk for heart conditions, sleep apnea, and vision problems;
- » Higher risk for Alzheimer’s disease; and
- » Higher risk for seizures.

Of particular note are the wide range of individual differences in their abilities, learning of new skills, and challenges.<sup>1-10</sup>

**Alzheimer’s disease** is a probable diagnosis of the most commonly occurring progressive dementia given after a full medical examination. In the general population, the typical decline of Alzheimer’s disease occurs first in short-term memory and recalling words, and/or difficulty completing complex tasks or making complex decisions. Other early signs include disorientation to time and place; more difficulty using both hands together to do skilled, complex tasks such as winding a clock, using a key, or buttoning a shirt; and difficulty completing daily routine tasks. Later changes may involve personality such as becoming more irritable, or the opposite, more withdrawn, and, still later, decline in movement such as walking (see more information later in this chapter and in the *Chapter 7: Alzheimer’s Disease Overview*).

**Related dementia** refers to other progressive conditions, such as vascular dementia, frontal-temporal dementias, or parkinsonisms (movement disorders with progressive dementia). Decline from these conditions may create different patterns of decline in the following:

- short-term memory;
- language, such as recalling and understanding words when speaking, listening, writing, or reading;
- visual spatial skills, such as identifying direction or distance to objects;
- movement such as walking up stairs and skilled hand movements (i.e., using tools);
- executive functions such as planning, organizing, and problem solving; and

- personality (more irritable and outgoing or, the opposite, more withdrawn).

The decline in related dementias may differ from the patterns usually seen in Alzheimer's disease but also leads eventually to the point of people being unable to handle their typical daily routines, responsibilities, relationships, and eventually, personal care.<sup>1-10</sup>

### ***Brief History of Down Syndrome***

Descriptions of intellectual and developmental disabilities were described as early as 1550 BC in *The Therapeutic Papyrus of Thebes*. Centuries later Jean Etienne Dominique Esquirol in 1838 and Édouard Séguin in 1844 reported similar observations.<sup>5</sup> However, the English physician John Langdon Down, motivated by his grandson who had the condition, described the physical and intellectual characteristics in more detail in 1866, which led to the condition being called Down syndrome.<sup>6</sup>

In 1959 the French human geneticist Jérôme Jean Louis Marie Lejeune discovered the irregular triple-chromosome, an extra copy of Chromosome 21, thus the term Trisomy 21.<sup>3</sup> Based on the observation of three people with Down syndrome (ages 37, 42, and 47) and findings from examining their brain tissue, George A. Jervis, M.D., published (1948) the first report in English linking Down syndrome with Alzheimer's disease.<sup>8-16</sup>

### ***Occurrence of People With Down Syndrome and Alzheimer's Disease***

More than 400,000 people in the U.S. have Down syndrome. Longevity has increased not only for the general population but also for people with Down syndrome. With changes in laws, policies, health care, and greater efforts to keep people with Down syndrome home- and community-based, about 80 percent of people with Down syndrome reach age 60 or older according to the National Down Syndrome Society ([www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome](http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome)). Similar to all adults, with increasing age the person with Down syndrome has a greater risk to develop Alzheimer's disease or a related dementia.

According to the National Task Group on Intellectual Disabilities and Dementia Practices (2014): "Some individuals with select conditions (Down syndrome, in particular) are more at risk for dementia, experience earlier age of onset, more rapid decline, and a briefer duration between diagnosis and death."<sup>17</sup>

Associated with increased biological aging (accelerated epigenetic clock<sup>18</sup>), the risk to develop chronic diseases increases with Down syndrome. Research suggests that compared to the general population, people with Down syndrome have five or six times the occurrence of Alzheimer's disease, are more likely to develop younger-onset Alzheimer's disease by 35 to 40 years of age, have a different presentation of initial signs of decline, may undergo brain cell changes specific to people with Down syndrome, suffer a faster rate of decline, and are at greater risk for seizures especially in the late stage of Alzheimer's disease.<sup>6, 8-13</sup>

Many researchers have noted individual differences in their studies of brain tissue from people with Down syndrome and Alzheimer's disease. Some people while alive functioned as if they did not have Alzheimer's disease though the brain tissue showed changes associated with Alzheimer's disease. In other cases of people with Down syndrome who were diagnosed with Alzheimer's disease, they did not have the expected amount of changes when the brain tissue was later examined.<sup>14</sup>

### ***Importance of Good Brain Function***

People with Down syndrome should lead as healthy a lifestyle as possible to keep their brain working well. The following table lists basic ways to keep the brain healthy. Regular medical check-ups of adults who have an IDD, e.g., Down syndrome, should note in medical records the usual healthy levels of function and personality, handling of responsibilities and routines, self-care, and adjustment to change.

### ***Basics of Keeping the Brain Healthy***

- Good daily nutrition: protein, whole grains, fresh fruits, and vegetables.
- 10-12 glasses of water (or similar liquids) daily unless a physician limits liquids.
- Positive interactions, enjoyable relationships, quality time with others, and time alone.
- Physical exercise, especially walking or bicycling, for at least 30 minutes at a time for at least five days a week.
- Daily brain exercise: crossword, jigsaw, and math puzzles; reading and talking about what was read; music; handcrafts; planning and doing tasks; etc.

- Daily purposeful (useful and meaningful) tasks whether at a job or at home.
- Fun activities.
- Reduced unpleasant stress.
- Following the physician's and dentist's advice for good health!

For middle-age and older adults who have Down syndrome or other IDD and who have access to regular medical visits for chronic health problems (i.e., changes in vision or hearing; pain; weakness; shortness of breath; heart or blood circulation problems; muscle, joint, or bone problems; diabetes; etc.), the follow-up medical exams should include and note in the medical record other changes. Other changes that occur in relationships, mood, or personal care, or completing routine tasks, may indicate the beginning of Alzheimer's disease or a related dementia.

In the next comparison table, note the differences when typical early signs of Alzheimer's in a person with Down syndrome are compared to typical early signs of Alzheimer's or a different dementia in the general older population.

The NTG-EDSD (National Task Group-Early Detection Screen for Dementia), filled out before the annual medical exam by the caregiver or someone well-acquainted with the person who has Down syndrome, helps to identify decline in function and health in a person over age 40. The form has six pages and is available with directions on the internet ([www.aadmed.org/ntg/screening](http://www.aadmed.org/ntg/screening)). The form is free and offered in English, Dutch, French, German, Greek, Italian, Japanese, Scottish, and Spanish.

Several key health care considerations for people with Down syndrome are as follows:

- average age of onset of Alzheimer's disease is 20 years earlier than the general population;
- incontinence occurs in 87 percent of people with Down syndrome and Alzheimer's disease and related dementia;
- gait changes occur in 97 percent of people with Down syndrome and Alzheimer's disease and related dementia;
- dysphasia (difficulty swallowing) occurs in 58 percent of people with Down syndrome and Alzheimer's disease and related dementia;

Comparing Early Signs of Alzheimer's Disease or Related Dementia	
People With IDD or Down Syndrome	Older General Population
<b>EARLY CHANGES IN THE FOLLOWING:</b>	
<ul style="list-style-type: none"> <li>- Personality, such as being more irritable and aggressive or more withdrawn and passive</li> <li>- Refusing to cooperate in activities or tasks</li> <li>- Mood, such as acting sad, no longer interested in previously enjoyed activities, decline in appetite, sleep, or self-care</li> <li>- Handling interactions</li> <li>- Doing (or not completing) routine tasks</li> </ul>	<ul style="list-style-type: none"> <li>- Short-term memory</li> <li>- Recalling specific words while talking</li> <li>- Losing or misplacing objects; getting lost</li> <li>- Difficulty making decisions involving many choices</li> </ul>
<b>LATER CHANGES/DECLINE MAY APPEAR IN THE FOLLOWING:</b>	
<ul style="list-style-type: none"> <li>- Short-term memory</li> <li>- Language</li> <li>- Decision-making and other thinking functions</li> </ul>	<ul style="list-style-type: none"> <li>- Completing tasks</li> <li>- Personal care</li> <li>- Personality – becoming more irritable or, the opposite, more passive</li> <li>- Movement ability</li> </ul>

- hypothyroidism (low thyroid): though the thyroid develops normally in children with Down syndrome, it stops working in 50 percent of adults with Down syndrome, which may increase the risk for progressive dementia;
- obstructive sleep apnea is common in people with Down syndrome and may increase the risk for progressive dementia;
- late onset seizures are much more common (79 percent) in people with Down syndrome than for the general population (2 percent); and
- rapid-decline forms of Alzheimer's disease can lead to death less than two years after onset in adults with Down syndrome.

More information is available in Health Care Guidelines for Individuals with Down Syndrome<sup>19</sup> and The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities.<sup>20</sup>

### *Summary: Signs of Decline*

Any change from the person's own normal way of functioning should be of concern. The typical cooperative, competent behaviors may change to uncooperative, resistant, withdrawn, or irritable behaviors. The person undergoing the changes may or may not be aware of changes and difficulties or may deny any problems with function. Someone else such as a family member, teacher, or supervisor who knows the person well may be the first one to notice changes.

Later decline may occur such as decreased memory, speech or word use problems, not understanding directions or explanations, or not completing tasks. Changes may occur in empathy or mood swings. A seizure may occur for the first time. If the person with Down syndrome who is typically happy, competent at their daily routine, and a pleasant team member on the job or at home then becomes withdrawn, irritable during interactions, and unwilling to cooperate with team members or a supervisor, a medical exam is important.

## **The Medical Evaluation**

A full medical exam should be done by a specialized physician who is knowledgeable in the assessment of people with progressive memory disorders such as Alzheimer's disease and related dementia. The first reason is to rule out and treat a fixable problem. Not everybody with memory problems has Alzheimer's disease. The second reason is to offer treatment, management strategies including educational materials, and links to community resources such as caregiver support groups, adult day care, and other supportive services, etc.

Some people with changes in memory and thinking functions may improve with medical treatment as in cases when there is pain such as a sore tooth or joint aches, an infection such as a bladder infection, a vitamin B12 or thyroid deficiency, or a new medicine that may be having an anti-memory (anticholinergic) effect. A relationship change such as a best friend moving away, a job change, a change of caregiver, or death of a pet, friend, or family member may lead to depression resulting in a person with Down syndrome experiencing problems with memory and being unable to do routine tasks.

Changes in the setting, support from loved ones, supportive resources and programs for the diagnosed person and the family, talk therapy, and mild anti-depressants may work to return the person with Down syndrome to previous healthier levels of function.

### *Full Medical Exam*

A full medical exam for the person with Down syndrome who is having changes in personality or function should include some of the points listed in the following table. A careful exam is necessary to identify all the conditions such as diabetes, low thyroid, or high blood pressure that may benefit from medical attention. Important also are blood tests and pictures of the actual brain to include brain imaging such as an MRI (magnetic resonance imaging) or CT (computer tomography).

## *A Full Medical Exam*<sup>19-21</sup>

A full medical exam should consider the following:

- Current symptoms and changes in function: what has been the regular level of function and what changed first, second, third, etc.? When did change occur?
- Health history including past developmental history, genetic conditions, chronic health conditions, medical and surgical treatments, trauma (especially head injury), special diets, etc.
- A review of all the health & function changes, e.g., heart, vision, hearing, skin, gastrointestinal system, incontinence, sexual function, dental health, etc.
- Social history, education completed, special job training skills, employment/work/retirement history
- Health history of directly-related family, such as parents, grandparents, siblings, uncles, aunts, etc.
- History of substance abuse (tobacco, alcohol, leisure drugs, etc.)
- Physical exam including blood pressure, weight, pulse (and sometimes temperature)
- Specialty medical exams when needed, such as neurology, neuropsychology, cardiology, urology, oncology, speech/physical or occupational therapy, etc.
- Psychosocial assessment
- List of prescribed and over-the-counter medicines, vitamins, herbs, teas, etc.
- Tests of small samples of blood and urine, imaging such as MRI, or CT, etc.\*
- Other tests as needed, i.e., breathing tests, stress test, EKG, EEG, EMG, chest x-ray, sleep study, spinal tap, etc.\*

\* *MRI – magnetic resonance imaging (brain imaging)*  
*CT – computer tomography imaging (brain imaging)*  
*EKG – electrocardiogram, a study of heart function*  
*EEG – electroencephalogram, a study of brain function*  
*EMG – electromyogram, a study of nerve function in the muscles*

## *Medical Recommendations*

A careful medical evaluation may point to the need for lifestyle changes, such as improved diet, increased physical activity, etc. (see the earlier table, Basics of Keeping the Brain Healthy). The doctor may recommend a change from a medicine such as an allergy medicine or incontinence medicine that blocks memory function and suggest treatment strategies or other medicine that treats the problem without weakening memory function. Based on the results of the medical evaluation, some physicians may change some medicines that could be affecting memory function, prescribe medicine that may help memory function, and offer special care management strategies such as simplifying tasks, keeping a routine, regular physical exercise, and reducing stress.

In people with Down syndrome, there seems to be a strong link between Alzheimer's disease and seizures. Researchers have noted also a steeper rate of cognitive decline.<sup>12</sup> Seizures occur in 90 percent of people with Down syndrome who are in the severe stage of Alzheimer's disease, whereas about 15-25 percent of others (without Down syndrome) have seizures during the severe stage of Alzheimer's disease.<sup>13</sup> Thus, special planning should include education regarding signs of seizures, seizure management, early signs of medicine not controlling seizures, lining up backup help, and identifying other resources to help if seizures occur.

The medical recommendations should also include strategies and limits to address general safety issues such as the following:

- Ongoing decline due to Alzheimer's disease may result in problems operating a motor vehicle such as a car, motor boat, riding mower, or golf cart; therefore, it may be time to limit or stop some or all of these activities.
- Decline in memory may result in a person losing objects, leaving doors open or unlocked, forgetting to shut off the stove or water faucet, or becoming lost on regular walks or bike rides through the neighborhood; therefore, labeling personal items such as jackets, wallets, etc., checking doors and the bathroom after use, and working together to cook and do other tasks or activities should increase safety.
- Problems with balance may result in falls or tripping on loose rugs, stairs, sidewalks, or curbs; therefore, remove loose rugs, repair stairs, loose

doorknobs, cabinet shelves; smooth out uneven surfaces on the floor, sidewalk, yard, etc.; apply balance bars and handrails; keep the setting well lit, etc.

- Clumsy hand skills may lead to injuries when using sharp tools (i.e., a razor, knife, scissors, needle, pin, screwdriver, etc.); therefore, it may be time to avoid sharps and use smoother tools such as an electric shaver or blunt-nose scissors.

### *Tips for Caregiving*<sup>20-23</sup>

The health care team should provide tips and resources that provide good information for home-based and community-based care management. Alzheimer's and related disorders (ARD) typically progresses more quickly in people with Down syndrome, but the symptoms and decline in function are similar to the general population. Families should take advantage of the resources and educational programs available in the Alzheimer's care community. Care management at home or a community program should involve simplifying tasks and the setting to accommodate changes in function while helping the person to maintain as much independence and control as possible. Opportunities should allow the person to make choices, continue useful activity, relate easily to others, and keep up with self-care in a safe setting. A routine should include some variety in a simple schedule of activities with periodic rest times.

It is important for the person with IDD and Alzheimer's disease to have a healthy lifestyle which includes physical exercise such as pet care, walking (outdoors or on a safe treadmill, with a friend or buddy, or on a nature walk) or safe bicycling (outdoors or on an exercise bike) five days a week. Group activities such as bowling, folk dancing and freestyle dancing, exercise to music, and miniature golf provide great physical exercise.

Daily brain exercise should be varied, such as word games; puzzles; board and card games; doing art work (drawing or painting); playing musical instruments; singing with a group; acting out a simple play, story, or song; reading with a friend (reading buddy); etc. Also stimulating for the brain are keeping up to date with family news and events and helping to plan upcoming family events such as birthdays and holidays. Interesting discussions with family and friends could cover the following:

- special, meaningful events – local art fairs, exhibits, community programs, events at a place of worship or meditation, or outdoor events;
- T.V. and radio shows – sports, music, comedy; and
- family activities and visitors (practice their names before they arrive).

Key tips for the person with IDD who has Alzheimer's disease are as follows:

1. keep the schedule simple, routine, and meaningful; and
2. be positive – keep activities and interactions interesting, positive, and fun.

### *General Tips for the Person With IDD and Alzheimer's*

1. Keep reminder notes and a calendar in one place.
2. Stick to routine schedules for daily, weekly, and monthly activities as well as special events such as holidays or birthdays.
3. Keep paper and pen/pencil handy (or cell phone, iPhone, or smartphone if useful) in pants pocket or purse. When you think about it, write it down. Write down ideas, passing thoughts, tasks to do, people to call, etc.
4. Keep handy names and phone numbers of people who can help.
5. Work at paying attention. Watch; listen; focus; keep eye contact.
6. Repeat information out loud and a few times quietly to yourself to remember.
7. Do one task at a time, one step at a time, the usual way that you know well.
8. Go the way you know. Keep handy simple directions with large print (and a small, simple map), a picture of the destination or person(s) there, and the easiest way to return home.
9. Label with the first name and phone number of a contact person on/in jacket, eyeglasses, phone, book bag, purse, wallet, etc., in case the items are lost.
10. Remember to say please and thank you.

## *Assisting People Who Have IDD and Alzheimer's Disease*

The family and caregivers of the person with IDD and Alzheimer's disease should keep the schedule simple and routine. The caregivers should plan activities ahead of time; allow extra time for tasks or appointments; make the home, work, or leisure setting easy for daily functions; and schedule for themselves as well as the care receiver down-time as rest periods in-between varied activities or during a busy weekend. Creating a list of the tasks and activities should include ones that are fun and rewarding for the person with Down syndrome and Alzheimer's disease. It is important that the person continue to have activities that allow them to keep contributing to the home and family to the extent that they are able. The need to feel valued does not change once someone is diagnosed with Alzheimer's disease or a related dementia.

### *Tips for People Who Assist Those With IDD and Alzheimer's*

1. Keep tasks and activities simple, one step at a time.
2. Keep information, directions, or requests simple (few words). Discuss details briefly and use the actual names of people, pets, places, etc. Use specifics and repeat one or two important simple details. Rather than asking whether the person is hungry, use statements such as "Let's eat lunch!" Or more simply, "Lunch!"
3. Use a patient, pleasant voice, and repeat the question, request, or answer.
4. Keep a positive facial expression, voice, words; encourage, not nag. Avoid negative facial expressions or words, especially criticism or arguments.
5. Look for hidden meaning or feelings in the person's words or facial expressions.
6. Act as a team to organize a drawer, hang up clothes, fold laundry, do yard work, feed or care for a pet, etc.
7. Schedule time for tasks apart from each other, such as in separate rooms.
8. Allow extra time for a response, getting bathed or dressed, doing tasks, and meeting appointments.
9. Set aside or schedule regular rest times for each of you.

10. Hang a large calendar. Keep the daily schedule handy and follow it. Schedule daily tasks, activities, and exercise at routine times. Mark off what is done and past appointments. Keep that page or file for later reference.
11. Post at an assigned, regular place (i.e., bulletin board, refrigerator door, or bedroom or bathroom wall or mirror, etc.) a sign; a simple, brief list; or a picture to note special activities or tasks.
12. Encourage regular physical exercise such as walking 30 minutes at a time, five days a week.
13. Schedule daily fun brain exercise: puzzles, cards, board games, computer games, books, outdoor activities, etc.
14. For someone who loses clothes or objects, label items with a first name and contact phone number.
15. Remember to say please and thank you.

Family members or significant others should try to stay as positive as possible. Maintaining a communication style that is pleasant, patient, and sensitive to preferences helps the person with Down syndrome and a progressive dementia to maintain a sense of being the following:

- valued,
- self-sufficient,
- independent or somewhat independent, and
- an important contributor to the activities in the work and home settings.

As symptoms progress and behavior is affected, keeping a positive attitude and communication style is not always easy. It is important to seek out caregiver education on issues such as communication and behavior management. Joining a local caregiver support group is highly recommended. In a support group or educational class, a caregiver should listen and ask questions about how to handle challenging situations, frustrations, and stress. The caregiver should ask about information on local services and resources, free online resources, and how to find them.

### *Caregiver Respite*

Caring for a person with Down syndrome and Alzheimer's disease offers personal rewards such as a sense of accomplishment that comes from keeping someone safe and supported, an opportunity to build bonds with a

loved one or other caregivers, and the knowledge that you have helped someone to feel the joy of a success and doing meaningful activities. A good supply of hugs is another benefit. Over time the continuous oversight and the often unexpected challenges of caregiving may build stress in the caregiver and tax her/his health. As the person with Down syndrome and Alzheimer's disease declines, the caregiver takes on more responsibilities and tasks, often to the point of neglecting personal well-being. To continue to be effective, the caregiver must maintain physical, emotional, and spiritual health.

Respite, regular time out from care duties for the caregiver with pleasant, non-caregiving activities, is essential. (Refer to the chapter: Stress Management for Caregivers for more information on this important topic.)

## Planning Ahead<sup>20-23</sup>

Besides early interventions to stop or slow down memory and cognitive decline, another value of an early medical evaluation of the person with Down syndrome is the ability to plan ahead with the family for future lifestyle adjustments. Early on, assistance from medical, legal, and financial professionals; social workers; and geriatric care managers may help to identify resources and supports and to establish priorities. Early planning to fulfill the wishes and to understand clearly the preferences of the person with Down syndrome and Alzheimer's disease while function and thinking are at good levels could include the following:

- Listing preferred visits to or from friends, valued relatives, or others;
- Identifying favorite types of music, especially calming or relaxing music;
- Recalling memorable events that were pleasing and favorite pastimes (to use later to help with conversations and other interactions);
- Identifying preferred routines and self-initiated activities; and
- Discussing likes and dislikes in foods, beverages, dress, activities, tasks, movies, books, relatives, colors, music, etc.

While communication, decision-making, judgment, and other executive function skills are at their strongest is the time to discuss issues and preferences of the person with Down syndrome and Alzheimer's disease. This informa-

tion will become important later when the person's function depends on caregivers providing much more or full personal care. Planning ahead should consider legal, financial, and possible long-term needs, such as health care surrogates for decisions and health care preferences.

People with Down syndrome and early Alzheimer's disease may already have difficulty making decisions. If not, they are considered to be competent regarding health decisions unless determined and declared to be otherwise. Concerns about durable power of attorney for health, finances, and legal decisions as well as guardianship should be addressed in the early steps of planning ahead.<sup>18,19</sup>

Other topics to consider include accessing resources and creating a plan of care for the family or other caregivers to provide leisure activities, emergency and medical services, life enrichment classes, and increased assistance with homemaker services or personal care over the long-term.

There are currently very limited options for specialized day programs or residential facilities with highly trained staff that specialize in care for people with Down syndrome and Alzheimer's disease. Families and other caregivers should identify what is available in their community and investigate the costs and eligibility criteria to determine the potential role in the long-term care management of the person with Down syndrome and Alzheimer's disease whose abilities decline as changes occur. Even if a caregiver plans to keep someone at home indefinitely, it is important to have a back-up plan (caregivers need respite, a break to visit their other family out-of-town, or may become ill). Thus, caregivers need to know and gather information about options, such as gathering brochures and visiting day programs, agencies with in-home services, day care centers, and residential facilities.

Plans for the future should include housing alternatives as abilities change. Backup plans for care should be developed because, over time, caregivers such as elder parents experience changes in health and the ability to oversee responsibilities including the care of their loved one with IDD and Alzheimer's disease. The backup plan should provide for a sudden need such as the caregiver suffering an emergency health crisis or a chronic care need such as the caregiver being unable to provide at-home care. The backup plan should include details that cover care for the elder parent(s) as well as the person with Down syndrome and Alzheimer's disease. Other family caregivers, e.g., siblings, other relatives, paid caregivers, or volunteers from

local programs, may be necessary for brief or more long-term assistance to manage future care.

In some cases, the plan for future overnight care for a weekend to provide respite for the caregiver or full 24/7 care may need to include a facility. A dementia-friendly residence or a community-for-a-lifetime should offer a full continuum of dementia-friendly services that include independent living, limited assistance, memory care, skilled rehabilitation, and nursing care. Very few programs currently have staff who have special expertise in working with people who have Down syndrome and Alzheimer's disease.

End-of-life care and decisions should consider the preferences of the person with Down syndrome, the family culture, resource people in the community, and programs that are accessible and available to provide support.

Accessing resources for educational purposes and identifying services and programs such as specialized day care programs to help the caregiving family are important. Plans for improvements in the care system available to those with Down syndrome and Alzheimer's disease are underway in Florida. The first step has been to provide education for professional and non-professional caregivers and to set up a model program which is overviewed briefly in the next section.

## **The Florida Model: Addressing Dementias**

### ***Addressing the challenge for Floridians including people with IDD, especially Down Syndrome, and Alzheimer's Disease or a Related Dementia***

Many Floridians with IDD will experience Alzheimer's disease or related dementias in middle or later adult life. As mentioned before, people with IDD such as Down syndrome typically have different early signs of Alzheimer's disease or a related dementia. Often they display initial changes in behavior, mood, or personality; relationship difficulties; difficulty with or being unwilling to follow directions, difficulty doing routine tasks at work or home, and decreased self-care. After a while decline affects short-term memory, disorientation to time and place, getting lost in familiar places or losing items, and eventually, requires total, daily personal care.

Alzheimer's disease and related dementias are devastating conditions that dramatically increase caregiver burden. Families involved in the daily care management of someone with Down syndrome may become overwhelmed with the growing demands. The additional, increasing responsibilities and challenges may overwhelm and exhaust many aging parents or caregivers who are developing their own serious health issues.

***The National Alzheimer's Project Act includes people with intellectual disabilities, especially Down syndrome, a targeted group protected and considered "specialized."*** (<http://aspe.hhs.gov/daltcp/napa/>)

The National Alzheimer's Project Act (NAPA), which the U.S. Congress passed unanimously in 2010, called for a national action plan to address issues related to Alzheimer's disease and related dementias in 2014. The NAPA also created a federal advisory council for overseeing NAPA activities including a special focus on persons with IDD, especially Down syndrome, and Alzheimer's disease or related dementias:

"Some populations are unequally burdened by Alzheimer's disease. People with Down syndrome almost always develop Alzheimer's disease as they age. In addition, because Alzheimer's disease primarily affects older adults, the population with younger-onset Alzheimer's disease faces unique challenges with diagnosis, care and stigma." (*National Plan to Address Alzheimer's Disease: 2013 Update; Appendix 3; [aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml](http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml)*)

Along with the federal effort was the creation of the National Task Group on Intellectual Disabilities and Dementia Practices to ensure a lifelong approach to address the dementia-related needs of adults with IDD and their families. The National Task Group on Intellectual Disabilities and Dementia Practices Co-Chairs, Matthew P. Janicki, PhD,<sup>24</sup> and Seth M. Keller, MD,<sup>25</sup> joined Thomas J. Buckley, EdD,<sup>26</sup> in partnership with the Florida Department of Elder Affairs to propose the formal designation of Down syndrome and intellectual disabilities as specialized. In addition, they created a national pilot program in Florida at the Lucanus Developmental Center in Hollywood, Florida.

## *The Florida Plan: Addressing Dementias – Florida Leadership in Specialized Alzheimer’s Care*

A team from the Florida Department of Elder Affairs in collaboration with the Lucanus Developmental Center developed a Florida Plan, to model the first U.S. specialized, comprehensive dementia-capable system of services with a network of supports. The initiative ends marginalization and eliminates institutions as the only option for people with IDD and a diagnosis of Alzheimer’s disease or a related dementia. The Florida Model: Addressing Dementias calls for the creation of the following:

- specialized dementia-capable services and supports;
- formal, specialized, evidenced-based curriculum for aging caregivers and workforce; and
- first formal, specialized caregiver support groups created to support the aging caregiver(s) suffering from the death of their child while they provided total care with no dementia supports.

In 2013 staff at the Broward Health North Memory Disorder Center, the National Task Group on Intellectual Disabilities and Dementia Practices, the Florida Department of Elder Affairs, and the Agency for Persons with Disabilities developed the Florida Model: Addressing Dementias curriculum, a formal, specialized person-centered curriculum to educate the workforce. The curriculum addresses respite, day services, meals, transportation, and early diagnostic protocols implemented through Florida’s hallmark <sup>15</sup> Alzheimer’s Disease Initiative Memory Disorder Clinics/Centers, which include the Broward Health North Memory Disorder Center.

The unveiling of the nation’s first formal, evidence-based, Florida Model: Addressing Dementias curriculum was honored with the participation of Erin G. Long, the Social Science Analyst responsible for creating specialized dementia services and supports in the U.S. Health and Human Services, Administration for Community Living (ACL), Center for Program Operations (<http://www.hhs.gov/ogc/contact/contacts.html>).

On July 6, 2014, the U.S. Department of Health and Human Services received a grant application from the Florida Department of Elder Affairs, the Florida Agency for Persons with Disabilities, the Lucanus Developmental Center, and several other collaborators (i.e., Broward

Health North Memory Disorder Center; Nova South-eastern University College of Medicine GEC [Geriatrics Education Center]; CARES [Comprehensive Assessment and Review for Long-Term Care Services] Tampa Bay, the Alzheimer’s Association-Florida Gulf Coast Chapter; and Easter Seals). Valuable assistance came from Drs. Janicki and Keller, Co-Chairs of the National Task Group on Intellectual Disabilities and Dementia Practices. The purpose of the grant was to create the nation’s first formal specialized, dementia-capable system providing services and supports for Americans with IDD, especially Down syndrome, and Alzheimer’s disease or a related dementia.

The National Task Group on Intellectual Disabilities and Dementia Practices support letter to the U.S. Health and Human Services stressed that, “The national specialized ADRD model created in Florida will be emulated across the nation enabling all Americans living with an intellectual disability, especially those with Down syndrome and Alzheimer’s disease, and their aging caregivers the opportunity to access quality person/family-centered dementia-capable services and supports while aging in place.”

Initiating the plan for the *Florida Model: Addressing Dementias*, specialized pilot training program related to Alzheimer’s disease or a related dementia on the west coast of Florida were the following:

1) Christine Powers, Director of Community and Aging Retirement Services and Adult Day Services, Tampa, Florida, and Chair of the Florida Alzheimer’s Disease Advisory Committee, oversaw specialized day care, respite, homemakers, and geriatric counseling through Community and Aging Retirement Services (CARES) and the Alzheimer’s Association-Florida Gulf Coast Chapter.

2) Kathleen J. Houseweart, MBA, Manager of Geriatric Services, Coordinator of the Memory Disorder Clinic at the Sarasota Memorial Health Care System, provided through the Alzheimer’s Disease Initiative Memory Disorder Clinic (Sarasota Memorial Health Care System). Partnerships linked to the Alzheimer’s Support and Education Network in Sarasota, Florida, and the Jewish Family & Children’s Services (Sarasota) that targets the ID/DD population with dementia.

## *Florida Model: Addressing Dementias – Emphasis on Higher Quality*

*(Note: High quality refers to the Advisory Council on Alzheimer’s Research, Care, and Services meeting in 2014 addressing the national concern for high quality dementia services and supports. See [aspe.hhs.gov/advisory-council-alzheimer%E2%80%99s-research-care-and-services-2](http://aspe.hhs.gov/advisory-council-alzheimer%E2%80%99s-research-care-and-services-2))*

In December 2014, the Florida Agency for Persons with Disabilities under Director Barbara Palmer, MA, sought information regarding comprehensive specialized person/family-centered, community-based services and supports for Floridians with Alzheimer’s disease or a related dementia and their aging caregivers. Director Palmer joined forces with Samuel P. Verghese, Secretary of the Florida Department of Elder Affairs, to create the nation’s first *High Quality-Specialized, Person/Family-centered Dementia-Capable Services and Supports Model*.

Some components of this Agency for Persons with Disabilities-Department of Elder Affairs joint planning highlighted the following:

- Access to 24-hour, in-home supports for caregivers with the following:
  - » Home health services,
  - » Meals preparation,
  - » Housekeeping services,
  - » Companion services,
  - » Respite care,
  - » Adult day services,
  - » Transportation,
  - » Memory Disorder Clinic/Center services, and
  - » Abuse/Neglect/Exploitation Protection Services;
- Development of alternative living;
- Access to training/education and resource information; and
- Targeted screenings and assessments.

## *Florida Commitment to Dementia-Friendly Communities*

A multitude of Floridians living with IDD, especially Down syndrome, will experience the debilitating effects of Alzheimer’s disease and related dementias, because though treatment is available, no cure exists at this time.

The Florida governmental leadership, the Florida-wide 15 Alzheimer’s Disease Initiative Memory Disorder Clinics/Centers and three associated adult day care programs, the Florida Governor’s Committee on Alzheimer’s disease (the Purple Ribbon Task Force), the National Task Group on Intellectual Disabilities and Dementia Practices, and the Lucanus Developmental Center continue tirelessly to create the specialized person/family-centered dementia-capable services and supports that Florida families need desperately. The goal of Florida is to serve its families as the paragon leader of Dementia-Friendly Communities, which are as follows:

- informed, safe, and easy to navigate;
- technologically advanced with high quality, meaningful dementia-capable services and support options;
- respectful of all Floridians suffering with Alzheimer’s disease; and
- providing quality in life to families and aging caregivers while they age in place.

Several national and Florida groups have collaborated to develop a statewide plan and have launched the pilot, a model of Florida High-Quality Specialized Dementia-Friendly Communities including but not limited to the following:

- Public awareness, information;
- Accurate and timely diagnosis, medical management, and treatment;
- High quality dementia care coordination;
- Future planning;
- Meaningful day activities;
- Specialized dementia-friendly transportation; and
- Specialized dementia-capable settings for persons with young onset, IDD (e.g. Down syndrome) Alzheimer’s disease or related dementias.

## Summary

People with lifelong intellectual and developmental disabilities (IDD), such as Down syndrome, have a wide range of individual differences in their abilities and learning of new skills. Down syndrome is associated with intellectual and physical delays, a higher risk for heart conditions, sleep apnea, and accelerated aging. Compared to the general population, people with Down syndrome appear to be at greater risk to develop Alzheimer's disease, have onset at a younger age (during young or middle-age adult years), decline at a faster rate than the general population, and are at higher risk for seizures, especially during the advanced stage of Alzheimer's disease.

A problem with short-term memory is usually the first sign of Alzheimer's disease in the general population. However, people with Down syndrome have different early signs of Alzheimer's disease or a related dementia. Often they display initial changes in behavior, mood, or personality; difficulty with or unwillingness to follow directions; struggles doing routine tasks at work or home; or decreased self-care. After a while decline may be evident in short-term memory, language skills (speaking, understanding, reading, or writing) and other thinking functions such as decision-making or completing steps to a task.

Changes in the schedule, setting, and relationships may lead to increased sadness, irritability, or decreased interest in activities or social activities and present as a sign of depression or as an early sign of a fixable or progressive dementia in a person who has Down syndrome or a different IDD. Behavioral and personality changes; depression; high anxiety; and high amounts of stress, fatigue, and problems with short-term memory, language, or other thinking abilities may result from infections, pain, inflammations, or some other "fixable" condition. After treatment of such conditions, some people with Down syndrome should return to their normal or close to normal level of functioning when they undergo a clinical evaluation six months later.

### *Importance of Early Medical Exam*

Any changes from the person's regular way of functioning may be signs that a person with IDD has developed a treatable dementia or a progressive dementia such as Alzheimer's disease or a related dementia/disorder. Thus, an early medical evaluation at the beginning of such changes in behavior and function is important. People with such changes, who are diagnosed with a progressive de-

mentia such as Alzheimer's disease, and who receive early treatment are likely to experience better and longer brain health and longer independence in their daily routines.

If the full medical evaluation indicates a diagnosis of Alzheimer's disease, the family should learn as much as possible about the condition and plan ahead as much as possible with the person who has the diagnosis. Several resources are available through internet links to identify educational materials and contacts that may provide services and support groups in the local community. The following resources and internet sites provide additional information about people with IDD, especially Down syndrome, and Alzheimer's disease or a related dementia.

## Resources

### *Websites on Alzheimer's Disease*

Administration on Aging: Washington, DC 20201; 202-619-0724; [www.aoa.gov](http://www.aoa.gov)

Alzheimer's Association: 225 North Michigan Avenue, 17th Floor, Chicago, IL 60601; 800-272-3900; [www.alz.org](http://www.alz.org); online support groups; free educational materials.

Alzheimer's Disease Education and Referral Center (ADEAR): PO Box 8250, Silver Spring, MD 20907; 800-438-4380; [www.alzheimers.org](http://www.alzheimers.org)

Alzheimer's Foundation of America (AFA): 322 8th Avenue, 7th Floor, New York, NY 10001; 866-AFA-8484 (866-232-8484); [www.alzfdn.org](http://www.alzfdn.org); [www.alzquilt.org](http://www.alzquilt.org) (a quilt to remember)

National Family Caregivers Association (NFCA): 10400 Connecticut Ave, Suite #500, Kensington, MD 20895; 800-896-3650; [www.nfcares.org](http://www.nfcares.org)

### *National Websites on Down Syndrome*

Down Syndrome Affiliates in Action: resource repository, education and training webinars, brokered discount programs and discounted registration at annual conference. 5010 Fountainblue Drive, Bismarck, ND 58503; 701-425-7129; [www.dsaia.org](http://www.dsaia.org); [info@dsaia.org](mailto:info@dsaia.org)

Down Syndrome Education USA: USA-based, education; [www.dseusa.org](http://www.dseusa.org)

Global Down Syndrome Foundation: 3300 East First Ave, Suite 390, Denver, CO 80206; 303-321-6277; [www.globaldownsyndrome.org/about-down-syndrome/words-can-hurt](http://www.globaldownsyndrome.org/about-down-syndrome/words-can-hurt); [info@globaldownsyndrome.org](mailto:info@globaldownsyndrome.org)

National Association for Down Syndrome: 1460 Renaissance Drive, Suite #405, Park Ridge, IL 60068; 630-325-9112; [www.nads.org](http://www.nads.org); [info@nads.org](mailto:info@nads.org)

National Down Syndrome Organizations: about four major national Down syndrome organizations; [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org)

National Down Syndrome Congress: information, advocacy, public policy leadership, encourages research, annual conference. 30 Mansell Court, Suite 108, Roswell, GA 30076; [www.ndscenter.org](http://www.ndscenter.org); 800-232-NDSC (6372) or 770-604-9500; Fax: 770-604-9898; [info@ndscenter.org](mailto:info@ndscenter.org)

National Down Syndrome Society: information, National Policy Center works with U.S. Congress and federal agencies on equal, public awareness campaign in My Great Story, The National Buddy Walk Program, 666 Broadway, NY, NY 10012, 800-221-4602; [www.ndss.org](http://www.ndss.org); [info@ndss.org](mailto:info@ndss.org)

### ***For People With Intellectual and Developmental Disabilities (IDD)***

American Academy of Developmental Medicine and Dentistry (AADMD): information for healthcare professionals who provide clinical care; AADMD, PO Box 681, Prospect, KY 40059; [aadmd.org](http://aadmd.org)

Commission on Accreditation of Rehabilitation Facilities (CARF): accredits more than 50,000 programs and services at 23,000 locations. International. 888-281-6531; [www.carf.org/home](http://www.carf.org/home)

National Task Group on Intellectual Disabilities and Dementia Practices (NTG); provides advocacy, education and training, and informational materials related to people with IDD affected by Alzheimer's disease and related dementias; [www.aadmd.org/ntg](http://www.aadmd.org/ntg).

### ***Florida Resources: Florida Department of Elder Affairs (DOEA)***

Florida Elder Helpline (Florida Department of Elder Affairs – Elder Helpline): 800-963-5337; [elderaffairs.org/doea/elder\\_helpline.php](http://elderaffairs.org/doea/elder_helpline.php)

Florida DOEA ADI (Department of Elder Affairs, Alzheimer's Disease Initiative): 850-414-2000, [www.elderaffairs.org](http://www.elderaffairs.org)

### ***International Websites on Down Syndrome***

Down Syndrome Education International: United Kingdom based: education; [www.dseinternational.org](http://www.dseinternational.org)

International Down Syndrome Coalition (IDSC): free, accurate information about informed consent regarding pregnancy-related screenings and diagnostic tests; 901-413-2047; [idscc.information@gmail.com](mailto:idscc.information@gmail.com); [www.theidscc.org](http://www.theidscc.org)

International Down Syndrome Organizations: [www.ds-int.org/organizations/downs-syndrome-association](http://www.ds-int.org/organizations/downs-syndrome-association)

### ***Suggested Readings***

Moran, Julie. (2013). *National Down Syndrome Society. Aging and Down Syndrome: A Health and Well-Being. Guidebook*. NY, NY. 800-221-4602 · [www.ndss.org](http://www.ndss.org). <http://www.ndss.org/PageFiles/2594/Aging%20and%20Down%20Syndrome%20A%20Health%20and%20Well-Being%20Guidebook.pdf>

CARF (Commission on Accreditation of Rehabilitation Facilities) International. *2014 Aging Services Standards Manual*. CARF International is an independent, nonprofit accreditor of health and human services. Tucson, Arizona, Toll-free: (888) 281-6531; TTY: (520) 495-7077; [www.carf.org](http://www.carf.org)

*Healthcare Guidelines Record Sheet in English*, courtesy of Anna and John J. Sie Center for Down Syndrome (PDF)

*Healthcare Guidelines Record Sheet in Spanish*, courtesy of Anna and John J. Sie Center for Down Syndrome (PDF)

Smith, David S. Health Care Management of Adults with Down Syndrome. American Family Physician Guidelines for Adults with Down Syndrome. *American Family Phy-*

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3. <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability> Frequently Asked Questions on Intellectual Disability, Intellectual Disability. (accessed 1/25/16)
4. <http://www.thearc.org/learn-about/intellectual-disability>. Intellectual Disability. (accessed 1/25/16)
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11. Zigman, W.B., Devenny, D.A., Krinsky-McHale, S.J., Jenkins, E.C., Urv, T.K., Wegiel, J., Schupf, N., & Silverman, W. Alzheimer's disease in adults with Down syndrome. *Int Rev Res Ment Retard*. 2008 January 1; 36: 103–145.
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- A Full Medical Exam
- Alzheimer's Disease Overview
- Comparing Alzheimer's Disease, Cardiovascular Dementia, & Lewy Body Dementia
- Communication
- Helping With Daily Personal Care

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24. Matthew P. Janicki, PhD, (Research Associate Professor, Disability and Human Development, University of Illinois at the Chicago Rehabilitation Research and Training Center on Developmental Disabilities and Health, Chicago, Ill.

25. Seth M. Keller, MD; Neurologist at Advocare Neurology of South Jersey, Lumberton, N.J.

26. Thomas J. Buckley, EdD, Chair of Specialized Dementia Programs of the Agency for Persons with Disabilities & President of Lucanus Developmental Center, Hollywood, Florida.

# Chapter 10: Communication

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## **Purpose**

To teach the basic changes in communication abilities and ways to assist communication as Alzheimer's disease or a related memory disorder progresses.

## **Objectives**

Upon completion of this session, individuals will be able to do the following:

- Understand the changes in communication that occur in the three stages of Alzheimer's disease or a related disorder.
- Identify differences between verbal and nonverbal communication.
- Know ways to help people who have Alzheimer's disease and decreased language abilities to communicate with caregivers and others.
- Know ways to help caregivers communicate with persons who have Alzheimer's disease and decreased language abilities.

## **Basics of Communication**

Communication involves an exchange of information between people. The exchange involves the ability to take in and express messages. In communication, listening, which involves receiving and understanding messages, is important, but also important is the ability to send messages and give information to others. Exchanging information connects people to each other and thus is important for healthy relationships. Such exchanges help people to express needs such as hunger, wants such as a desire to go for a walk, and feelings such as appreciation of and love for each other.

Communication may be one-way, such as when listening to a radio program. The communication may be two-way, such as when two people have a conversation.

## **Verbal Communication and Nonverbal Communication**

There are two basic types of communication: 1) verbal communication and 2) nonverbal communication. Verbal communication involves words. Nonverbal communication involves body movements, such as arm and hand gestures, and facial expressions that occur during communication.

Verbal communication may involve words that are spoken by a person or heard on the radio or television. Songs add words to music to send strong messages. Words may be written or read in a newspaper or book.

Nonverbal communication may involve facial expressions, arm gestures, and loudness or quietness of voice. Watching a speaker's eye expressions and arm or shoulder movements gives information about the person's feelings or concerns. A glaring look of disapproval and shrug of shoulders may clearly and quickly show that a person is upset. The position of the body, such as facing or turning away from the listener, carries important information.

Sometimes the nonverbal message adds to the verbal message, such as when a person agrees and uses a nod of the head, pleasant words, and a smile at the same time. The nonverbal message may differ from the verbal message such as when someone agrees with words but then frowns, tightens jaw muscles, and looks away with an expression of anger.

Pictures may help to communicate information or an idea. The common saying, "A picture is worth a thousand words" gets across this message. Pointing to a photo or pictures can give a clear, strong message. Pointing to or drawing a "smiley face" that shows a smile or a frown can show a clear positive or negative message.

## **Communication Changes in Alzheimer's Disease and Related Disorders**

People who have Alzheimer's disease or a related progressive disorder have changes in communication. As the disease slowly gets worse over time, the ability to communicate gets worse. Such changes in communication affect the ability to do the following:

- Understand what other people say.
- Store words that are heard or read.
- Recall specific words that a person wants to use when speaking.
- Write letters, notes, or a shopping list.

For example, early in the decline, the person with Alzheimer's disease may struggle once in a while to do the following:

- Recall the names of neighbors or friends or a brand name of a car;
- Use the exact word when talking or writing;
- Correctly pronounce some words; and
- Spell words correctly in a note or phone message.

As the decline continues for a few years, they may struggle often to do the following:

- Follow the conversation of a group of coworkers or friends at a party;
- Follow the events of a friend's story or a news event on the television;
- Say the full word or right word when speaking;
- Use words in the correct order in a sentence; and
- Understand written words.

And much later as decline continues, they may struggle constantly to do the following:

- Recall the names of close family members even when seeing them every day;
- Understand the name and use of an object from someone's description; and
- Follow more than one step of directions at a time, such as during bathing.

Finally toward the end of the decline, they may not do the following:

- Understand any of the words that others speak; and
- Speak in words.

## *Circumlocution*

Circumlocution is a roundabout way to describe a word. As a way to get around being unable to recall the exact word, a person with communication problems may talk all around the word or talk about the word but not use the exact word. Many words may be used to describe the person without ever saying the exact name of the person. For example, the speaker may describe the red haired neighbor next door, how that neighbor plays with and walks the family dog, and many other activities of that person, and never use the correct name "Pat Brown."

The speaker with dementia may explain and even use hand gestures to show how something works such as pretending to hold and use a pencil but not say "pencil." Frequent circumlocution is an early sign of brain cell changes.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

## **Progressive Communication Disorders**

Alzheimer's disease, which begins typically with memory problems, is the most common form of progressive dementia. However, there are some progressive dementias that begin with major changes in language abilities. These language disorders may be a different type of progressive dementia.

As time passes, some language disorders may show only a problem with speaking words while other language disorders have difficulties that spread through speaking, understanding the speech of others, reading, and writing. Many times, however, a language disorder may progress to include declines in memory and different thinking

functions. Eventually the language disorders and additional dementia may look a lot like Alzheimer's disease.

Two of the progressive language disorders that occur are discussed in the next section. The disorders are as follows:

- Primary Progressive Aphasia
- Semantic Dementia

### *Primary Progressive Aphasia*

In *primary progressive aphasia*, the person gradually has more difficulty expressing words. The condition typically appears in middle age adults and comes on slowly. At first the person may have difficulty finding the right word when speaking. The person may recall and use the correct word but insert the wrong letters when saying (or writing) the word. As the condition progresses, the person may start to use incorrect grammar. Usually the person is aware of the speech errors and tries to correct them.

Despite working hard to speak correctly, people with primary progressive aphasia may be very slow to speak a word or to say a complete sentence. This slow speaking has led to some doctors to call primary progressive aphasia a *nonfluent aphasia*.

Sometimes difficulty speaking is the only problem especially early in the decline. In other words, there may be no problems with memory or other thinking abilities. Often as the years pass, people with primary progressive aphasia develop other thinking problems, such as short-term memory difficulty, problems making decisions, and being unable to do all the steps of daily, routine tasks.

### *Semantic Dementia*

*Semantic dementia* is another progressive language disorder. In semantic dementia, the person gradually loses the ability to understand the meaning of words. At first there can be a loss of understanding the meaning of words that are nouns and objects. Later the person loses the meaning of other words. Thus, as early decline occurs, they struggle to use the right word.

As the decline continues, there are difficulties recognizing or using simple, common words. While they may be able to repeat what they hear, they may not understand the meaning of the words. Thus they lose their ability to understand the meanings of words when others speak. It seems as if the dictionary in their brain has separated the

storage of words that they know from the actual definitions of those words.

Unlike the slow speech of primary progressive aphasia, the speech of semantic dementia usually flows at a normal rate without much effort. For this reason, semantic dementia is called *fluent aphasia*.

Essentially the decline of semantic dementia occurs over many years along the following path:

*Early on:*

- Occasional use of wrong words; and
- Occasional problems understanding the words and speech of others.

*Later on:*

- Using words that sound strange and do not make sense; and
- Speaking at a normal pace, tone, and with appropriate emotion, but sounding as if speaking an unknown foreign language.

*Much later:*

- Inability to express speech; and
- Inability to understand the speech of others.

Also, as the decline continues, other thinking problems may appear, such as:

- Memory loss;
- Being unable to use the hands and fingers in skilled ways such as tying shoes or using eating utensils; or
- Being unable to make decisions.

## **Communication Tips**

### *Ways to Help People With Language Difficulties to Communicate With Others*

Sometimes as people with Alzheimer's disease lose their ability to communicate, early on they are aware of the changes and then much later are not aware of their disabilities. People who are aware of the changes may try to cover up the problem by talking around the word (circumlocution) they cannot recall. They may try to write down what they want to say.

After several difficult times of struggling to communicate, they may become embarrassed or self-conscious with their difficulties. This discomfort may lead to withdrawing from interactions with others. They may act shy and not interested in the company of other people. Or, they may act anxious, frustrated, irritated, and angry. It may be hard for them to admit their new struggles. Also, it may be hard for them to use words to describe their frustration.

Some ways to help the person who has Alzheimer's disease and language difficulties to communicate include the following:

- Allow enough time for them to get out the words.
- Pay full attention with eye-to-eye contact. Be sensitive to cultural differences where strong eye-to-eye contact may be inappropriate. (Cultural differences are discussed at the end of this chapter.)
- Translate the sense of the whole message. Don't focus too much on one strange sounding word or missing words in the sentence.
- Think about the activities of the daily schedule to figure out what the person is requesting. For example, if it is mealtime, the confusing sentence may relate to hunger.
- Ask the person to point to what is needed or to a picture or photo.
- Ask the person to act out what they are trying to say.
- Ask them to shake their head "No" or nod their head "Yes" in response to your short sentence summary of their communication or to some simple questions.

### *Ways for Caregivers to Communicate With People Who Have Communication Difficulties*

One of the best ways to help the person with language difficulties is for the caregiver to repeat phrases and keep sentences brief and simple. In other words, sentences should be as follows:

- Sweet (using positive words);
- Short, only three to six words in a sentence;

- Simple words the person knows; and
- Spoken slowly.

Staying positive is important because a positive attitude is contagious. A positive facial expression with a smile, a positive relaxed body posture, using positive words, and a positive tone of voice will help keep the caregiver and the person with the language difficulty in a positive mood. Other tips for the caregiver to use include the following:

1. First, get the attention of the person with Alzheimer's disease by coming up to the side of the person, next moving to the front of the person, and then saying their correct name a few times. The caregiver should keep close (if culturally appropriate), make eye-to-eye contact (if culturally appropriate), speak in a clear voice, and use short sentences. Each short sentence should be given time to sink in and then repeated. The short sentence should have three to six words with the subject first, the verb next, and the object last.

**For example, saying,** "Mr. Tom (subject), please carry (verb) this book (direct object)."

**For example, not saying,** "Mr. Tom, before you carry the book to the coffee table, please wipe off the mud from your shoes, and change to your slippers, which are by the door."

2. Directions should be simple and given one step at a time.

**For example, saying,** "Take your toothbrush."

**For example, not saying,** "After you clean your teeth, comb your hair, and dress, we will have breakfast."

3. Be direct.

**For example, saying,** "We will buy shampoo."

**For example, not saying,** "We will pick up a few other things at the store when we buy the shampoo, and we will check out their sales."

4. Ask simple questions that can be answered with one word or "yes" or "no."

**For example, saying,** "Do you want hot oatmeal?"

**For example, not saying,** “What should we have for breakfast with all these good choices we bought during our shopping spree yesterday?”

5. Stay away from slang.

**For example, saying,** “I will drive the car. You will ride in the car.”

**For example, not saying,** “We will come around and pick you up at 9 for the appointment.”

6. The words should be concrete, that is, naming real objects or people, not abstract ideas.

**For example, saying,** “The sun is hot today.”

**For example, not saying,** “The brightness outdoors is blinding and hot enough to roast a person.”

7. Refer to the sense systems, such as seeing, hearing, smelling, tasting, and touching, to talk about objects or people.

**For example, saying,** “This rose smells sweet.”

**For example, not saying,** “The atmosphere is filled with so many floral fragrances.”

8. Use words that are at the level of or at a simpler level of the listener’s understanding (note the 7 examples above: “The rose smells sweet” is easier to understand than the sentence that follows it. Typically, words with one or two syllables usually are easier to understand than words with four or more syllables.

9. Speak slowly. Words that are spoken too fast may be hard to follow.

10. Use nonverbal actions to communicate:

**a.** Use positive, nonverbal behaviors such as a smile, head nods, and gentle arm and hand gestures.

**b.** Point to objects or people or use photos and pictures to show what or whom you are discussing.

**c.** Use a pleasant, positive, warm, relaxed voice. Speak slowly. A harsh, loud, hurried voice may send a strong negative message even when the words are positive.

## *A Peaceful Place to Help Focus*

Communication, especially important conversations that involve making decisions or explaining changes in the daily routine, should occur in a peaceful setting. Sitting in a quiet room or corner of a room with a folding screen for privacy helps the person with Alzheimer’s disease or a language disorder to communicate. In the home, to avoid the distraction of a family pet, the pet should be kept in another room during the conversation. In order for the person with the language difficulty to give full attention to communication or a task, the person should not face a window, art on the wall, other interesting pictures on tables, little children, or other distractions. General suggestions to set up a peaceful setting include the following:

- Closing the door to avoid seeing or hearing other people;
- Staying away from snack and beverage machines, and elevators;
- Closing windows to avoid the sounds of traffic, children playing, and outdoor animals chirping, barking, etc.; and
- Shutting off the radio, T.V., loud speaker, cell phone, dishwasher, oven or stove (odors from cooking food may be distracting), etc.

## *Cultural Issues*

People who come from different countries or different areas of the same country may have different traditions and cultures. For example, people from large cities may differ from people who come from rural areas in the ways they behave and show courtesies. An example of ethnic differences: Hispanics and Latinos may express feelings of illness in ways that differ from other cultural groups in the United States. Respect should extend to diverse religious practices, such as for Haitians who practice communication with spirit people or Native Americans who value shamans.

Respecting cultural differences means that direct eye contact in some cultures shows respect while in other cultures direct eye contact for more than a few seconds at a time shows disrespect, aggression, or anger.

Ask the family about cultural courtesies. For example, ask the family about the appropriate, respectful way to address a person, such as using Miss, Mr., Mrs., Dr., or some other acceptable term. In some cultures the family may

use a special first name that is an intimate “family name” and not correct for non-family use. Showing respect for the person with Alzheimer’s disease who is struggling with communication is important for positive interactions, especially when providing hands-on care for them.

## Summary

As a way to summarize tips to communicate with a person who has lost the ability to recall words or to speak, remember **KISSS**:

**Keep It Sweet, Simple, and Short.**

Also, set up the best conditions for talking:

1. The best setting: The best place is quiet and peaceful in a small group.
2. The best state of mind: The best state of mind is rested and fresh.
3. The best way to talk:
  - a. Say the most important thing first. Be direct. Be brief.
  - b. Keep the patient’s attention. Talk “eye to eye” (if culturally OK).
  - c. Talk slowly; give patient time to understand. Repeat.
  - d. Use everyday words, short statements, and simple grammar.
  - e. Use specific words: names of people and objects.
  - f. Do not use abstract, general words or pronouns.
  - g. Do not use metaphors (describing a likeness).
  - h. Give correct order (subject + verb+ object) when talking.
  - i. Discuss one action – one step at a time.

To help the person who has language problems to understand, the caregiver should:

- Use hand signals. Point. Show pictures. Speak clearly and slowly.

- Write or draw a picture.
- Ask questions that need “Yes’ or “No” answers.

To help the person who has language problems to talk or respond, the caregiver should ask the care receiver to:

- Point. Show with an arm and hand. Write or draw it.
- Act out the request or need. Use facial expression to show meaning.
- Try singing the message or directions.

# Chapter 11: Helping With Daily Personal Care

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## Purpose

To briefly describe ways to help a person with Alzheimer's disease or a related memory disorder with daily personal care such as eating, bathing, dressing, walking, sleeping, and toileting.

## Objectives

Upon completion of this session, individuals will:

- Understand the importance for the person with Alzheimer's disease or related disorder to be and feel as self-sufficient as possible.
- Learn the challenges of personal activities of daily living when someone has Alzheimer's disease or a related memory disorder.
- Learn respectful and useful ways to help a person with Alzheimer's disease or a related memory disorder handle activities of daily living such as eating, bathing, dressing, walking, sleeping, and toileting.

## Supporting Self-Sufficiency

Being and feeling self-sufficient involves managing one's responsibilities and taking care of oneself on a daily basis. It refers to having a sense of the following:

- Independence;
- Carrying one's own weight regarding responsibilities at home, work, etc.;

*Remember*, dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

- Choosing preferences of food, clothing, tasks, etc.;
- Interacting well with others; and
- Controlling one's own schedule.

Being self-sufficient helps a person to feel worthwhile, respected, and valued. With the decline of a progressive dementia such as Alzheimer's disease or a related disorder, it becomes more challenging to be and to feel self-sufficient. Caregivers may help a person with dementia to feel self-sufficient by doing the following:

- Learning about the disease, expected changes over time, and practical ways to help the person with dementia. Meeting with other caregivers, reading educational materials, and attending programs will help.
- Asking and observing the person with the condition before starting a task or during the task to discover what help is needed.
- Team up with the person who has dementia (as well as another person when needed) for a care-team approach to a task.

Central to being and feeling self-sufficient is not needing others to take care of one's daily, personal needs such as eating, bathing, dressing, walking, sleeping, or toileting.

## Offering Choices

To help people with progressive dementia to feel self-sufficient, the caregiver should encourage them to do as much as possible for themselves. It may take somewhat longer, but the benefits far outweigh the small extra invest-

ment of caregiver time. The caregiver can provide to the person with dementia a sense of control by offering choices, such as the following:

- Which of two activities to do first;
- Which step of a task to do first; and
- Which part of the task the care-receiver will do and which part of the task the caregiver may do.

### *Acting as Assistant*

Another approach is for the caregiver to act as an assistant to the person with dementia. An expression of appreciation from the caregiver allows the care-receiver to gain a sense of making the decisions and choices. The caregiver's words and body language should show kindness and respect. For Example when the caregiver says, "Thank you for letting me help you with dinner," the care-receiver gains a sense of being in control.

### *Simple Directions*

The caregiver should give simple directions or explanations. Short, simple repeated sentences about what is going to happen will help the person with dementia to focus on the next step of the task. When telling a person who has dementia about an upcoming activity such as a meal, simple positive words and short sentences work, for example, use the following short directives:

- "Lunch time."
- "Time to eat."
- "Here is lunch."

### *Simple Setting*

Simplifying the task may help the person with severe dementia. At mealtime, eating is easier when there is one utensil, one bowl of food, and one beverage. For example, after setting up one spoon, one bowl of cereal, and one glass of juice, the caregiver can set the spoon in the person's hand to start the activity. Showing how to move the spoon to one's mouth may help. The person with dementia should do any part or step of the activity that they can handle.

Even simpler is to set out only one bowl of simple finger foods. The person with dementia may be able to hold a

small piece of biscuit to nibble on as the caregiver feeds the person the other food.

### *Positive Approach*

The caregiver should focus on making positive comments. Body movements should be relaxed (not quick unless there is a safety issue). A smile will keep the caregiver's facial expression positive and should bring out a smile in the care-receiver. Mild, soft background music may help a person relax, enjoy, and focus on the activity. However, a quiet setting without music or other noise may work best.

### *Timing*

By observing the best time of day for an activity, the caregiver can identify the best time for meals, tasks, personal care such as bathing, or errands outside the home. That best time should become the daily routine time for that specific activity. People with Alzheimer's disease or other related dementia often function better in the morning after breakfast and are more tired and function more poorly at the end of the day. Thus, it may be better to schedule their daily bath or wash-up time in the morning to help them start their day. However, a bath helps to relax some people and thus a bath, shower, sponge bath, or foot soaking in the evening may be a good way for them to wind-down before going to bed.

## **About the Caregiver**

It is easier for the caregiver who is rested, not too stressed with worries, and who is not carrying heavy loads of responsibility to act with respect and kindness. A family or paid caregiver who is suffering from fatigue, stress, depression, overwork, and sleeplessness may become more impatient and irritable over time.

Having an ongoing sense of humor, a helpful network of family and friends, helpful teammates, good health, balance in life, good nutrition, regular exercise, time for oneself, and links to hands-on community resources and programs will help the family (or paid) caregiver manage well over the long term.

### *Rewards and Burdens of Caregiving*

Caregivers may experience many personal rewards from providing service to others, whether a family member, friend, or client. Caregiving develops the following:

- New skills and knowledge.
- Inner strengths such as patience, perseverance, flexibility, and feeling useful.
- Self-esteem from making a significant difference in the life of another.
- New memories of positive caregiving experiences.
- Stronger caregiver and care-receiver ties and family ties.

At the same time caregivers may experience burdens from the following:

- Constant care for someone else.
- Physical (back injuries), mental, and spiritual exhaustion, illness, or burnout.
- Growing sense of loss.
- Bills for increased services and supplies.
- Criticism from others who think they know better ways to provide care (and don't).
- Potential for abuse, exploitation, or violence of care-receiver or caregiver, especially in relationships that have a past history of problems.

Planning ahead for caregiving tasks may mean changes from previous routines to new routines. Setting boundaries should limit stressors such as undesirable demands from others or unnecessary tasks. Planning in extra time to do routine tasks can accommodate the unpredictable such as a seasonal flu or house repair problems. Bringing in extra help before it is obviously needed can help to avoid the caregiver becoming overwhelmed with tasks.

### *Showing Caring*

When people with progressive dementia no longer understand language, they rely on other people's behaviors, facial expressions, and tones of voice to understand directions and expressions of caring. Often a smile, a gentle appropriate touch to the arms or shoulders, or a few kind words will carry feelings of warmth and support from the caregiver.

### *Dealing With Negative Behaviors*

Ongoing decline of progressive dementia leads to more disability, which may easily frustrate the person with

dementia as well as the caregiver and other family members. These ongoing changes may lead to depression and disabilities that interfere with the abilities of the person with dementia and the caregiver to keep up with personal care. Frustration may build up to an anger outburst and aggressive behavior. The caregiver should work to remain calm, patient, positive, and steady when providing assistance.

At times, it may be appropriate to take a break from the task for several minutes. For example, the caregiver may need to leave the room for a few minutes and then return to the task later. In some cases, resuming the task the next day works better.

The caregivers should recognize, encourage, and reward the positive behaviors of the care-receiver with words of thanks and a smile. On the other hand, to avoid strengthening negative behaviors, the caregiver should try to ignore any negative behaviors at the first sign that they are occurring. Distracting the care-receiver with strong positive stories, songs, or behaviors may work. It is important to remember that in most cases the negative behavior is not a normal response of that person. In many cases the imbalance in brain function results in the negative behaviors. Some suggestions to help include the following:

- Tag-team with another person for an A-B team approach. When the person with dementia refuses to cooperate, Caregiver A can step back (or leave) after Caregiver B (another person with a different style) steps in briefly to help with the task.
- Learn ways such as counting silently to 25, repeating out loud a calming proverb or poem, or singing a song to stay relaxed and to manage stress when tension builds during a task.
- Carry some pleasant ideas, stories, songs, pictures, or safe gadgets to distract the person who becomes irritable or resistant during a task.

### *Routines in Daily Personal Care*

As decline progresses, unfamiliar people, places, and activities, and unpredictable schedules may be confusing, too stimulating, overwhelming, or upsetting. On the other hand, routine can be comforting. For example, the following suggestions may help establish a reassuring routine:

- A daily schedule that includes regular times for awakening and sleeping, meals and snacks, bathing, dressing, use of the toilet (every two hours or less), doing laundry, walking the dog, outside exercise, medicines, etc;
- A weekly routine, such as shopping on Tuesdays and lunch with friends on Thursdays;
- Keeping the same arrangements for furniture inside and outdoors;
- Using the same color linens for the person's bed and bathroom; and
- Keeping clothes and shoes in the same places (though reduce the numbers of items).

## Good Eating

People need to drink enough water and have good nutrition every day. Unless a doctor restricts fluids, a person should drink 10 to 12 glasses of water (or similar healthy liquids) every day. A diet that carries a daily balance of vitamins and minerals should provide enough protein (meat, dairy products, and legumes), fresh fruits, and fresh vegetables.

### *Problems With Eating*

Problems eating may result from health changes that lead to the following:

- Forgetting how to prepare food;
- Forgetting how to unwrap, reheat, or serve food;
- Forgetting to eat;
- Dry or sore gums, teeth, tongue, or mouth;
- Poorly fitting dentures;
- Decreased sense of smell or taste; or
- Problems swallowing.

People who are suffering with depression or anxiety may have a decreased appetite. They may have the opposite such as an increased appetite with a constant hunger for unhealthy foods such as foods high in fats, sugar, and carbohydrates.

Some medicines may decrease appetite. People who use tobacco or drink large amounts of alcohol often feel less hungry.

Whenever there are big changes in weight or eating habits, the caregiver should pay special attention to the behaviors of the care-receiver such as the following:

- Amount and type of food eaten and avoided;
- Obvious difficulty when biting food, eating, or swallowing such as choking;
- Weight changes every week (or day); or
- Fit of clothing – too tight or too loose.

For the person who lives alone, someone else may offer to help with shopping, preparing food, or delivering prepared meals. A visiting family member or friend, who notices that the same food is in the refrigerator, bread box, cupboard, and pantry at the beginning and end of the week, should arrange for help. A telephone call to the person with dementia may serve as a good reminder that it is time for a meal or snack and where the food is located.

The food should be cut up before it is served. When the food is already prepared, on a dish, and readily accessible for easy eating such as on the table or kitchen counter in small sandwiches or bite-size pieces, the person with dementia may eat it more readily.

Six small meals may work better than three larger meals. Protein milkshakes and other drinks that are heavy in calories can help keep the weight steady for someone who is losing too much weight.

The room for eating should be restful without distractions such as from a television, phone, or pets. The quiet setting helps the person with dementia to focus on the activity of eating. A table setting such as a plain tablecloth that is a different strong color from the plate or bowl and one utensil keeps the setting simple. While the tablecloth and dish should be free of patterns, the shirt or dress of the person with dementia should have patterns and different colors to hide stains from food or liquids that spill.

The food should be a different color from the bowl to help the person to see and pick up the food. A sturdy cup with a large handle may be easier to grab than a glass. A bendable straw may help with drinking.

Dry, hard foods such as crackers and tortilla chips may be too difficult to chew and swallow. Small “active” foods such as peas, pasta, and rice may be hard to scoop up on

a utensil but may work well when served in a cream sauce that holds the small bits together.

## Bathing

A person with dementia may falsely “remember” that they just had a bath. Older people typically feel self-conscious when naked for bathing in the presence of others. The feedback systems in their brain that help them to be aware of their body odor, feeling sticky, or unclean may not be working so they may feel anxious or act shocked when someone else says it is bath time. Soothing background music during bath time may help them relax. An offer of a favorite snack or activity after the bath may keep the bath a positive experience.

A daily bath may not be necessary. A weekly visit with a hairdresser or barber can provide a good shampoo. A sponge bath, hand soak, or foot soak can extend to cleaning the whole arm or leg. During time on the toilet a quick washing of the groin area may work well.

When the person insists on wearing the same outfit every day, having several sets of the same outfit provides the comfort of sameness for the person with dementia. At bath time or bedtime the caregiver should immediately whisk away (out of sight, out of mind) the soiled clothes as soon as they are off, then quickly set out a clean set of the similar outfit.

It is important for the caregiver to lay out ahead of time all the materials for the bath and the clean clothing for afterwards. This would include the following:

- Wash cloth or bath mitt
- Towels
- Non-slip bath mat
- Floor mats/rugs
- Bath soap
- Shampoo and conditioner
- Dental care products, etc.
- Deodorant, body powder, body lotion, skin care products
- Clean clothes

Sometimes wearing a shower gown that opens in the back or on the sides can help the person with dementia to preserve modesty while providing the caregiver access for washing. A large towel can cover up the parts of the body that are not being washed. If the person with dementia wants privacy when washing their groin area, the caregiver may turn to look in the other direction and say that they are looking away to allow some privacy. Or the caregiver can stand at the edge of the room but should not leave the person with dementia.

Getting into a bath with more than a few inches of water may be terrifying as a result of losing the ability to perceive depth accurately. A tub seat, a side grab-bar, and special grab-bars will help a person climb into and out of a tub safely.

A sturdy shower chair (without the bucket that is used when the chair serves as a bedside commode) should have arm rests and open sides as well as an open space below the backrest. A hand-held shower may feel more comfortable than an overhead shower.

Before each step, the caregiver should describe in a mild, soothing voice what will happen next, such as, “I’m going to lift your leg and wash with this soft, warm, blue cloth.”

## *Tooth and Mouth Care*

Caregivers should encourage tooth care or mouth rinse after each meal. The caregiver may need to repeat each step of the directions. Or the caregiver may choose to do the task together with their loved one. If the person with dementia is unable to follow directions, mouth rinsing or a drink of water may be the best care that can be provided plus more frequent visits to the dental hygienist.

## Dressing

It is important for the person to get dressed in the morning for the day’s activities. Bedtime is the time to wear night clothes, not throughout the day. The caregiver may need to choose and set out clothing appropriate for the weather.

Choices for clothing in the bureau or closet should be few. The caregiver should offer help for the steps of dressing where there is a struggle. Choices should be between two or fewer items such as the green shirt or the brown shirt. Or the choice should be for one item at a time, such

as; “Do you want to wear the green shirt?” After a “No,” ask, “Do you want to wear the brown shirt?”

The clothing should be easy to put on and fit properly; beware of robes, pants, pajamas, or dresses that are too long. Clothing should feel comfortable to wear. Shoes should have flat soles and be easy to slip on. Unnecessary and extra clothing such as neckties or three-piece suits should be packed away or given away. Accessories such as jewelry should be restricted to pieces that are easy to fasten and wear. If there is a preference to wear the same outfit every day, then there should be several sets of the same outfit.

Except for meal time (when food spills can blend into shirt or blouse patterns), clothing should be plain or with simple patterns, clasps, or Velcro closures. Suspenders may replace belts for males. Slip-on clothing can prolong the self-dressing independence of the person with dementia. It may help to set up a routine with the dressing occurring in one place such as by the bed and the undressing occurring in another place such as the bathroom.

For dressing, the clothing should be set out, right side out, and in the order of putting on each item; thus the underwear will be on top of the pile of clothing. Each sock (tube socks are great because there is no front or back to them) should be on top of each shoe.

Problems dressing may include the following:

- Ability to do only one step of the task and needing a reminder about the next step;
- Forgetting what item of clothing fits where;
- Lost skills about how to handle or manage the clothing;
- Needing a great deal of time to dress; and
- Embarrassment about dressing with someone else’s help, presence, or reminders about the next action.

Some people with dementia may put on too many layers. It may help to keep heavy clothing locked up and only a few light pieces of clothing available during the hot summer weather. Other people with dementia will remove all their clothing several times during the day. It may help to put their clothing on backwards or with the fasteners in the back so that they cannot reach the fasteners such as snaps or hook-and-loop fasteners.

## Walking and Body Movement

Exercise keeps a body in good working condition. Walking is one of the best and easiest forms of exercise for aging adults. If the person with dementia walks with an unsteady gait or has trouble with balance, a physician should evaluate the person. Physical therapy for gait training may help to improve muscle strength, stepping, and balance. The therapy may help to relieve pain from sore knees and hips.

A person who is unable to walk should follow directions from a physical therapist to do chair exercises. Bed exercises may be appropriate. The person with dementia should wear a personal alarm (bracelet or necklace) in case there is a fall or other health crisis.

### *Home Safety*

A home visit from a physical therapist or occupational therapist can evaluate home safety and efficiency to keep the person with dementia as mobile and self-sufficient as possible. An elevated toilet seat, better lighting, removal of scatter rugs, reduced items in a closet or bureau, ramps, and handrails may increase home safety.

Furniture should remain in its usual spot but with wider spaces in between the pieces of furniture. Furniture should be sturdy to lean onto; such furniture helps to avoid a fall. Sharp corners on cabinets and tables should have soft coverings, available from hardware stores.

### *Wandering*

Some people with dementia wander. Sometimes the person is bored, restless, hungry, thirsty, or in pain and begins to pace or walk in the house, which provides good exercise. Wandering outside may be safe if the yard or patio are in a fenced locked area. The person may be dwelling in “the old days” and trying to walk or catch a bus to get to work. Or, the person may think it is urgent for them to go to the store for a special purchase. The person may be looking for their parents or an older sibling, who actually passed away decades ago. At these times, going for a walk in a limited or restricted area, doing gentle exercises, or doing a distracting activity may help.

### *Missing Person – Silver Alert*

If a person with progressive dementia is missing, whether they have wandered away on foot or in a motor vehicle, the caregiver should access the services of the *Florida*

*Silver Alert* program. There are two parts to the Florida program:

- The **State Silver Alert** program uses a statewide “alert system” to recover people with dementia who are missing after driving off in a motor vehicle.
- The **Local Silver Alert** program uses a local “alert system” to recover people with dementia who are missing as a result of walking, in other words missing “on foot.”

A summary of ways to search are:

1. First, search the immediate area where the missing person was last seen.
2. Next increase the search area.
3. Then, involve local law enforcement, by phoning 911 to report the missing person.

As soon as a quick search for the person reveals that the person is missing, the caregiver should phone 911, describe the missing person and the situation.

Procedures are in place to receive help from law enforcement and other community professionals to find the missing person quickly. After taking a few details, the law enforcement officer decides about activating a Silver Alert search. Depending upon the resources in the community, a Silver Alert search may involve alerting a network of community law enforcement officers such as officers in patrol cars, sending out notices to the public media, and activating a highway sign that displays a message.

If a person with progressive dementia tends to wander and get lost, it may be useful to take advantage of equipment to keep track of the person. Several types of equipment are available. For example, GPS (Global Positioning System which uses a satellite system to locate people or places), cell phone triangulation, radio frequency identification, and several other items are commercially available. Visit [www.floridasilveralert.com](http://www.floridasilveralert.com) for more details about the Florida Silver Alert programs and services.

## Sleeping

Healthy sleep is important because of the many functions that occur during sleep to keep the body healthy. Cell repairs, hormone releases, storing memories, and many

other important functions occur during sleep and are important to regular healthy functioning.

Too many nights of insomnia will change the day-night sleep cycle so that the person sleeps and naps more during the day. Thus the person may become more restless and awake during the night.

People with dementia who are sleepy during the daytime may be suffering from a health problem such as an infection or other problems such as sleep apnea (also called obstructive sleep apnea). Sleep apnea occurs when throat muscles relax during sleep and block the flow of air into the lungs. A full medical evaluation will identify the problem and suggest a treatment which uses a simple small, light plastic mask [Continuous Positive Airway Pressure (CPAP) machine with mask] that fits over the nose to keep a good air flow going into the lungs.

Helps for a good night’s sleep include the following:

- Bright light during the day either from the sunlight or from a bright lamp will help the person get enough light during the daytime so that when it is dark, their body will be ready for sleep.
- Getting up at a routine time in the morning and going to bed at a routine time at night. For people who need a nap, no naps after 2 p.m. Even a light cat nap in the evening may interfere with a night of full, good sleep.
- A very light bedtime snack may help to settle the stomach for sleep.
- No caffeine in coffee, tea, soda, or chocolate after 12 noon to allow the body enough time to remove the caffeine and its stimulating effect from the body before bedtime. Note that even caffeine-free coffee or tea (though not many herbal teas) have a small amount of caffeine,
- Some medicines may be activating or increase energy so those medicines should be taken early in the day. A doctor and a pharmacist are the best sources of information about the best time to take a medicine. Pain may awaken the person often at night. A night time dose of a mild anti-pain or anti-inflammatory medicine taken for a chronic painful condition such as arthritis may help sleep, and

- Physical exercise early in the day should help sleep.
- Relaxing a few hours before bedtime should help the person wind down.

The caregiver should remind the person with dementia who awakens during the night, wanders, and is ready to start the daytime activities that it is still night and time to sleep. It is important for the person with dementia to sleep well at night, because then the caregiver will also get a good night's sleep.

## Toileting

A schedule of using the toilet every two hours may help to keep the person with dementia clean and dry. Later in the course of the disease, an hourly schedule may be necessary. The caregiver should note signs showing the need to use the toilet such as the following:

- Restlessness,
- Pacing,
- Irritability,
- Pulling clothes at the groin area, and
- Starting to undress.

Side rails on the bathroom walls beside the toilet help the person to get down or up when using the toilet. Side rails that collapse when not in use allow more space for movement of the caregiver by the toilet. Having pre-torn pieces of toilet tissue or special wipes readily available may help the self-cleaning activities of the person with dementia. Hand washing reminders for afterward may be essential.

When the person with dementia begins to urinate in the wrong container such as a wastebasket, plant holder, water fountain, or pet dish, these containers should be kept out of sight. Sometimes placing a picture on the door of the bathroom helps to identify the right room. Applying a toilet seat that raises the level of the seat may make it easier to sit down and then stand up when done. Placing a piece of bright fabric that is a different color from the rest of the toilet (and the floor) on the toilet seat or toilet bowl rim will help to identify the target.

During the second stage (of the three stages of Alzheimer's disease) incontinence may begin. Not being able to

wait long enough to reach the bathroom, forgetting where the bathroom is located, or difficulty holding back urine may lead to incontinence. A urinary tract infection may lead to frequent trips to the toilet and leaking. A medical evaluation can help to find a treatable condition such as a bladder infection, constipation, a side effect of medicine, vaginal infection (in women), a prostate problem (in men), or a prolapsed (fallen) bladder.

Helps for incontinence include the following:

- Frequent (scheduled) toileting,
- Keeping the path to the bathroom clear and well lit,
- Using a urinal or bedside (or chair-side) commode (it may help to keep a urinal under a small blanket cover in the basket of a walker or a scooter or beside the chair with nearby wipes),
- Machine-washable bed pads (with cloth side-handles for easy moving) can serve also as chair pads and floor pads. Bed pads tucked under the side of the mattress and over the edge of the bed will catch drips,
- Absorbent underwear helps. "Adult diapers" is an insulting, embarrassing term and should not be used,
- A split-front toilet seat, made for males, helps them use the toilet.

## Summary

It is important to provide caregiving in a way that preserves the dignity and self-sufficiency of the person with Alzheimer's disease or related disorder. With a respectful, flexible, and patient approach, the caregiver can help the person who has dementia with activities of daily living such as eating, bathing, dressing, walking, sleeping, and toileting.

Being self-sufficient helps a person to feel worthwhile, respected, and valued. With the decline of a progressive dementia such as Alzheimer's disease or a related disorder, it becomes more challenging to be and to feel self-sufficient. Caregivers may help a person with dementia to feel self-sufficient by teaming up with the person who has dementia to do daily tasks and other activities.

## *Eating*

Daily nutrition depends on drinking enough water and eating foods with a balance of vitamins and minerals (protein, fresh fruits, and fresh vegetables) every day.

The person who lives alone may need help with shopping, preparing food, reminders about eating, or having ready-to-eat foods easy to access. A quiet setting and a simple table setting with bite-size foods or finger foods may improve eating.

## *Bathing*

At bath time or bedtime the caregiver should immediately whisk away (out of sight, out of mind) the soiled clothes as soon as they are off, then quickly set out a clean outfit.

Sometimes wearing a shower gown that opens in the back or on the sides or covering up with a towel can help preserve modesty. Getting into a bath with more than a few inches of water may be terrifying as a result of losing the ability to perceive depth accurately. A tub seat, a side grab-bar, and a special grab-bar will help a person climb into and out of a tub safely. A sturdy shower chair (without the bucket that is used when the chair serves as a bedside commode) should have arm rests and open sides as well as an open space below the backrest. A hand-held shower may feel more comfortable than an overhead shower. Daily tooth and mouth care are important. More frequent visits to the dental hygienist will help to keep the mouth, gums, and teeth clean and healthy.

## *Dressing*

Every morning the person with dementia should get dressed and use nightwear at bedtime. Choices for clothing in the bureau or closet should be few. The caregiver should observe the person with dementia to determine when help is needed in picking out appropriate clothing or dressing. The clothing should be easy to put on, fit properly, and feel comfortable to wear. Shoes should have flat soles and be easy to slip on. Unnecessary and extra clothing and difficult-to-fasten jewelry should be avoided. Except for meal time (when food spills can blend into shirt or blouse patterns), clothing should be plain or with simple patterns, clasps, or Velcro closures.

## *Walking and Body Movement*

Exercise keeps a body in good working condition. Walking is one of the best and easiest forms of exercise for aging adults. If the person with dementia walks with an unsteady gait or has trouble with balance, a physician should evaluate the person. Physical therapy may improve gait, muscle strength, and balance.

A physical therapist may recommend daily chair exercises or, where appropriate, bed exercises. A physical therapist or occupational therapist can evaluate home safety and efficiency to keep the person with dementia as active as possible.

Sometimes the person with dementia is bored, restless, hungry, thirsty, or in pain and will pace in the house or wander outside. The person may be dwelling in “the old days” and trying to walk to work or to the bus stop to do an errand. They may be looking for their parents, who may have passed away decades ago. At these times, going for a walk in a safe (locked space such as the yard), doing gentle exercises, or doing a distracting activity may help.

## *Missing Persons and Silver Alert Help*

If a person with progressive dementia is missing, whether they have wandered away on foot or in a motor vehicle, the caregiver should access the services of the Florida Silver Alert program. As soon as a quick search for the person reveals that the person is missing, the caregiver should phone 911, describe the person and the situation. Procedures are in place to receive help from law enforcement and other community professionals to find the missing person quickly. Details about the Florida Silver Alert program are available at [www.floridasilveralert.com](http://www.floridasilveralert.com).

## *Sleep*

Healthy sleep is important because of the many functions that occur during sleep such as cell repairs, hormone releases, storing memories, and many other important functions.

People with dementia who are sleepy during the daytime may be suffering from a health problem such as an infection or other problems such as sleep apnea (also called obstructive sleep apnea). Aids for a good night's sleep include the following:

- Bright light during the daytime and a dark bedroom with a dim nightlight for safety;
- Getting up at a routine time in the morning and going to bed at a routine time at night;
- No caffeine in coffee, tea, soda, or chocolate after 12 noon;
- No medicines that increase energy (they should be taken early in the day only); and
- Physical exercise early in the day and relaxing a few hours before bedtime.

It is important for the person with dementia to sleep well at night, because then the caregiver will also get a good night's sleep.

### **Toileting**

A schedule of using the toilet every one or two hours may help to keep the person with dementia clean and dry. Signs showing the need to use the toilet include restlessness, pulling at their pants, or starting to undress. Side rails and special toilet seat fixtures may improve access and ease for use.

When the person with dementia begins to urinate in the wrong container such as a wastebasket or plant holder, these containers should be moved out of sight. A picture on the door of the bathroom may help to identify the right room.

Incontinence may begin during the second stage of Alzheimer's disease. Not being able to wait long enough to reach the bathroom, forgetting where the bathroom is located, difficulty holding back urine, a urinary tract infection, constipation, and other health problems can lead to incontinence. Helps for incontinence include frequent (scheduled) toileting, using a urinal or bedside (or chair-side) commode, and using absorbent underwear.

## **Resources and Recommended Readings**

Agingcare: [www.agingcare.com](http://www.agingcare.com)

Alzheimer's Association, Inc.: 1-800-272-3900; [www.alz.org](http://www.alz.org)

Alzheimer's Disease Education & Referral Center (ADEAR): 1-800-438-4380; [www.nia.nih.gov/Alzheimers/AlzheimersInformation/AboutUs.htm](http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/AboutUs.htm);

Alzheimer's Foundation of America: 1-866-232-8484; [www.alzfdn.org](http://www.alzfdn.org)

Alzheimer's Society. Carers Advice Sheet: Washing and Bathing. *Alzheimer's Society Dementia Care & Research*. November 2005.

Bradley Bursack, C. *Minding Our Elders: Caregivers Share Their Personal Stories*. [www.mindingourelders.com](http://www.mindingourelders.com)

Caregiver's Aide: <http://www.caregiversaide.com/>

Caring.com: [www.caring.com/articles/alzheimers-and-toileting-advice](http://www.caring.com/articles/alzheimers-and-toileting-advice)

ElderCare Locator. eldercare resources in the U.S. 1-800-677-1116. [www.alz.org](http://www.alz.org)

HelpingCaregivers: [www.helpingcaregivers.com/](http://www.helpingcaregivers.com/) - [info@helpingcaregivers.com](mailto:info@helpingcaregivers.com)

Levine C. (Ed). (2004). *Always On Call: When Illness Turns Families into Caregivers*. Nashville, TN: Vanderbilt University Press.

Ziff, S.M. & Schaffner, A.R. (2000). Occupational therapy student research of the needs and characteristics of dementia caregivers. In Perkinson, M.A. & Braun, K.L. (Eds). *Teaching Students Geriatric Research*. NY: The Haworth Press, Inc., p.29-40.

# Chapter 12: Strategies for Behavioral Challenges

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## **Purpose**

To teach how to deal with behavioral challenges in people with Alzheimer's disease or related memory disorders.

## **Objectives**

Upon completion of this session, individuals will be able to do the following:

- Identify some of the behavioral challenges/problems that are difficult for caregivers of people with Alzheimer's disease or related disorders to understand and manage.
- Learn more about and use Validation Therapy as a way to approach and interact with people who have Alzheimer's disease or related disorders.
- Use a three-step problem-solving model, the Three-Step Cycle, to help provide care when dealing with behavioral challenges of people with Alzheimer's disease or related disorders.

## **Behavioral Challenges**

In some, but not all, people who have a diagnosis of probable Alzheimer's disease or a related disorder, behavioral problems present challenges for self-care and caregiver management. Research identifies several behavioral problems that appear. Estimates of the types of behavioral problems in people with Alzheimer's disease or a related disorder show the following:<sup>1</sup>

- Agitation impacts 50-75 percent of people;
- Anxiety affects 30-50 percent of people;
- Depression affects 25-50 percent of people;
- Aggression affects 25 percent of people;
- Hallucinations affect 10-25 percent of people; and
- Lack of inhibition affects 20-35 percent of people.

Other behavior problems include the following:

- Difficulty sleeping;
- Changes in eating;
- Repeating actions and questions;
- Rummaging through drawers, boxes, closets, and leaving behind a mess;
- Restlessness, pacing, wandering, and getting lost;
- Inappropriate language; and
- Inappropriate sexual behaviors.

## ***Different Changes in Different Progressive Dementias***

It is important to remember that brain cell changes are responsible for new behavior problems that develop. Brain cell loss occurs in different areas of the brain in different progressive dementias and thus leads to different deficits and behavior problems.

For example, cell loss in the hippocampus of the brain such as in Mild Cognitive Impairment (often called MCI) and in early Alzheimer's disease leads to decline in short-term memory. As a result, people with these memory problems may become frustrated, anxious, or depressed as they more often do the following:

- Forget the names of a friend or specific words during a conversation;
- Struggle to manage complex tasks such as supervising staff, handling large meetings or family reunions; and
- Cannot balance the checkbook or keep up with paying monthly bills.

Later, as cell loss occurs in different parts of the brain, people with middle stage Alzheimer's disease may do the following:

- Get angry when unable to recall the name of a family member or more general words such as recalling that a pet is a “cat” or “dog” or an object is a “pencil” or “magazine”;
- Ask the same question over and over, which wears out caregivers; and
- Look repeatedly all over the bedroom or house for a lost object and refuse to switch to another necessary activity or task.

Cell changes in the frontal lobes, such as in Frontal Dementia, may result in the following:

- More spontaneous, inappropriate behaviors and language such as acting too friendly when talking with strangers or the opposite, unwilling to be with people or do activities;
- Doing the same action over and over such as dressing, undressing, re-dressing, re-undressing, etc;
- Not finishing tasks such as putting a leash on the dog to go for a walk, stopping to do something else, then forgetting to walk the dog;
- Moving, thinking, or speaking too slowly; and
- Having a new increased (or nonstop) desire for lots of sweets.

Frontal lobe changes as well as subcortical changes related to Vascular Dementia (or Cardiovascular Dementia) may lead to restlessness, wandering, aggressive behaviors, anger outbursts, or the opposite, withdrawal or inactivity.

A person with a progressive dementia that early on affects muscle control and movement (for example, walking and balance) and then later affects memory and thinking abilities may have Lewy Body Dementia or Parkinson's disease with Dementia. Less commonly occurring are related conditions such as Progressive Supranuclear Palsy or Corticobasal Ganglionic Degeneration. Since early in the decline people with these movement difficulties still have strong memory, language, and other thinking skills, they remember clearly how well and quickly they functioned previously. The current movement difficulties often lead to their frustration, growing worry, angry outbursts,

crying episodes, withdrawal from others, or depression.

## Validation Therapy<sup>2-8</sup>

Validation Therapy offers a method for caregivers to approach and relate to people with dementia in positive, respectful, gentle ways that affirm (validate) their feelings. Using the method of Validation Therapy can help caregivers to increase the alertness and redirect the attention and behaviors of people with dementia to positive, purposeful activities.

Validation Therapy grew from the work of a social worker, Naomi Feil, MS, ACSW, as a way to help people with Alzheimer's disease and related disorders. She felt that it was important to connect to the person with dementia in slow, gentle, positive ways. Validation Therapy connects in slow, soothing ways that accept someone's feelings as authentic and important and reflects those feelings back in gentle words that begin to gain the person's attention. Once the person pays attention (looking at or appearing to listen to the caregiver), the next step is to redirect that attention (or activity). In Validation Therapy, pleasant eye-to-eye contact, a positive facial expression, and repeated calming, simple words become important tools to connect to the person with dementia and shift their attention in another, positive direction.

When people become less able to understand language, they depend more on the behaviors and body language of others. Reading others' behavioral language such as facial expression, tone of voice, hand movements, and posture remains long after the loss of ability to understand words. The person who is reading behavioral language will notice frustration in the voice, stress on a face, and tension in the body. As a result, the person will react negatively to those behaviors such as a caregiver rushing to finish paying bills even though the caregiver may be saying positive, words such as, “It's time for a snack of ice cream.”

In summary, caregivers who apply Validation Therapy should:

- Use a positive, gentle approach.
- Respond to the emotion or facial affect of the person with dementia by reflecting the person's feelings with gentle, soothing words and actions.
- Slowly steer the attention of the person with dementia who is showing frustration or irrita-

tion to a new direction, topic, setting, or failure-free activity. Pay attention to safety issues. [Set up ahead of time “failure-free” activities such as a snack, a photo, or music, so that a distracter is right there to use.]

A person who has severe dementia may be dwelling in the past, reliving past experiences with people who have passed away decades before. Those old memories may be happy times. On the other hand, those memories may be sad times, unresolved regrets, or unfinished arguments. Some people may linger in the past as a time and setting that now offers security or makes them feel cared for, especially if the present setting is hard to understand, unpleasant, too difficult to manage, or makes them feel frail, vulnerable, or frustrated.

Validation Therapy does not contradict the reality of the person with dementia. It does not remind them about forgetting, being wrong, confused, frail, or demented. It does not insist that they stop their feelings or words. Validation Therapy respects the feelings and their dignity and redirects their attention. It redirects away from negative, stressful feelings to pleasant feelings. Validation Therapy helps a person to feel cared for, connected to someone else, and validated as a human being instead of being ignored, in someone else’s control, or in an unknown setting with strangers.

Finding a way to acknowledge the thinking of the people with dementia who may be dwelling in memories from their youth and linking those memories with current feelings can help them feel respected and valued. The validation of their feelings and the positive, non-threatening interaction can give them a sense of worth, respect, and dignity and shift them to pacing, wandering, stubborn persistence, and anger to a positive attitude and actions. Suggestions when doing Validation Therapy:

- Try to understand the underlying concern for the current feelings or behaviors. For example, ask the person pacing near a door, “How are you?” or “What is going on?” If they are worried about missing the bus to work, suggest that the next bus will come by after a while or that this is their day off. Then invite them to go with you for a beverage or to see a friend or to join people in the activity room who are making beautiful pictures, etc.
- Try to understand the words spoken. If the

words do not make sense, address the feeling and redirect them to a walk to look out the window at some flowers or a visit to the family room or activities room to find a friend.

- If the person is looking for someone or something, offer to walk with them to a couple of places to look and offer empathy about how hard it is sometimes to find people/things. Next suggest that the person or item will probably turn up in a few minutes. Then try to distract them with music, looking at a magazine, or going outside to look at plants, birds, or flowers.

## Simple Ways to Deal With Behavioral Problems

People with Mild Cognitive Impairment (often called MCI), or early Alzheimer’s disease may help their frustration with memory problems by using memory notebooks, small calendars, and repeating details three or four times to remember them. Reminders from co-workers or caregivers typically can help maintain daily routines on the job or at home. Caregivers should focus on the positive, schedule time for pleasant activities, and keep a pleasant, “can do” mood.

The confusion, disorientation, and help needed by people with moderate Alzheimer’s disease (or other dementias) increase struggles for them and caregivers. The caregivers should try to keep on the normal routine schedule and usual ways they handle daily activities. The person with dementia may act out in anger or in embarrassing ways during social situations especially when in public. They may lose their way or fall often in their own house. They may use objects incorrectly such as try to eat food with a knife, wash their teeth with soap, or hold a spoon upside down. They may enter the closet while trying to go outdoors or find the toilet.

Caregivers can help people with moderate Alzheimer’s disease or related disorders to function well by staying with the same routines as much as possible including the following:

- Routine for personal care such as bathing or dressing;
- Daily routines at home such as times to wake up, go to bed, eat meals, do house chores, take walks, do yard work, etc.; and

- Weekly routines outside the home, such as times and places for gasoline fill-ups, grocery shopping, worship services, meeting friends, etc.

People with severe dementia and minimal abilities need 24/7 care. Sometimes their frail state leads to frustration or depression which may result in their striking out at caregivers or refusing to cooperate. They may refuse to get out of bed, bathe, dress, or eat. Approaching them from the side in a gentle, positive manner, such as used in Validation Therapy, may work. A soothing voice from a caregiver that respects levels of hearing uses an appropriate name to get their attention, and a gentle, appropriate touch to their arm will help to identify the caregiver's presence as nonthreatening and comforting.

When approaching someone who does not appear to be alert, the caregiver should match the relaxed, slow rate of breathing and low intensity behavior of the person with dementia. Then gradually as the person with dementia stirs and increases a level of alertness, the caregiver should increase the level of interaction.

### *Safety Issues*

Unsafe areas of the house include cupboards holding cleaning fluids, rubbing alcohol, alcoholic beverages, and sharp tools such as knives or scissors. Also extra care for safety should occur with stairs, balconies, displays of frail glass dishes or figurines, and ceramics throughout the house. Safety-proofing the house, utility room, or garage includes using various locks or latches to lock up:

- Cupboards holding cleaning or other caustic liquids (cabinet latches);
- Doors to balconies or to the street (door knob cover-locks);
- Sharp instruments (drawer latches);
- Weapons and hunting equipment, such as guns with bullets removed, knives, swords, or archery equipment (double lock or give them away);
- Carpentry or repair tools (double lock or give them away); and
- Kitchen drawers or cooking appliances (plastic safety latches or magnet locks)

Locking up or gating off some areas as off-limits should include stairs, decks, hot tubs, wells, swimming pools, yard-gates, sheds, and green houses. Covers are available

at hardware stores for electrical outlets, stove knob-covers, and plastic edge-cushions to cover the edges of countertops.

## **Problem-Solving in Three-Steps**

Keeping up with different, challenging, and inappropriate behaviors may keep the caregiver on the run. The caregiver should adapt the home setting, yard, garage or carport, schedule, and interaction styles as decline of the disease continues. Understanding what sets off a problem behavior and strategies to address the behaviors should help the caregiver to manage over long-term decline.

In order to deal with the behaviors or to change the negative behaviors into positive behaviors, it is important to learn about what makes the behavior start and continue.

Some behavior problems relate to the type of decline, such as being unable to communicate a need or fatigue. Being thirsty, hungry, in pain, and overwhelmed by too much activity in the setting may set off behavioral problems such as frustration, anger, accusing words, yelling at or pushing the caregiver, or refusing to participate in any activity. Changes in the setting such as a different routine, something new in the setting (new furniture), a different outfit after a bath, or changes in the caregiver (such as a new hairdo or outfit) can trigger behavior problems.<sup>1</sup> Perhaps both the person giving care as well as the person receiving care experience Sundown Syndrome. (Sundown Syndrome refers to not thinking or functioning well and becoming more irritated towards the end of the day, as fatigue builds “when the sun goes down.”)

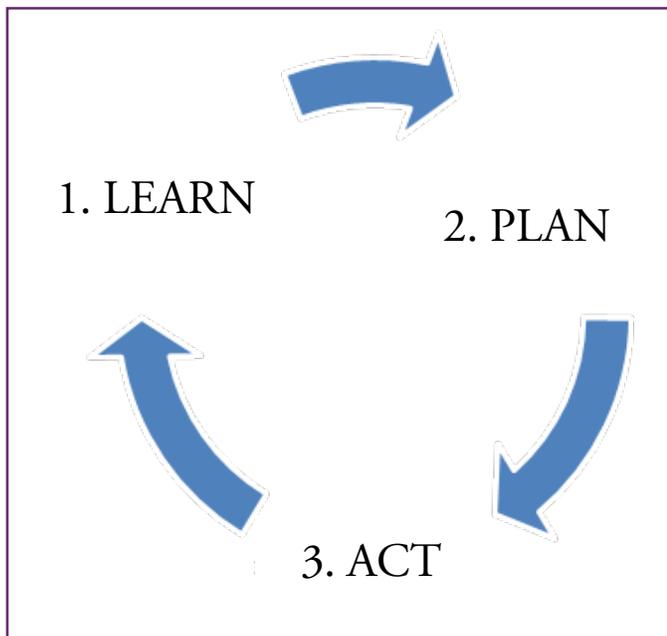
Exploring what starts the behavior problem is important to deal with the problem. The behavior problem may occur whenever the caregiver is out of sight, too slow to respond to a need or request, is busy at another task, or not giving full attention to the person with dementia. Sometimes as the caregiver becomes worried, stressed, or tired, changes occur on the caregiver's face or in body movements. The person with dementia may notice the signs of caregiver worry, interpret the signs correctly, and mirror those behaviors. The response to a serious look on the caregiver's face may be sadness, anger, or aggressive behaviors.

### *The Three-Step Cycle*

The Three-Step Cycle provides a strategy to help caregiv-

ers to handle challenging behaviors. The next section describes and applies the Three-Step Cycle to different behaviors that challenge caregivers. The three points of the Three-Step Cycle are:

1. **LEARN:** Understand the disease and related behavior changes, and observe to learn what starts the behavior problem in the person receiving care. In other words, learn.
2. **PLAN:** Think of a new method to handle the task or activity and to avoid starting the problem behavior. Break down the method into the smallest steps possible and match each successful step with a reward. In other words, plan.
3. **ACT:** Try out the steps of the plan. Reward the care receiver for each successful step. Then reward yourself. If a step of the plan does not work, rework the plan and try again. In other words, act.



### *Repetitive Behaviors*

Sometimes people with dementia repeat the same behavior and refuse to change their pattern of behavior. It may be a struggle for a caregiver to redirect them to a different behavior. The person with dementia may be “looking for a lost...” object or person such as a letter, dress, shoe, parent, sibling, best friend, etc. They may be poking around in drawers, boxes, waste baskets, piles of newspapers, closets, bookshelves, etc.

It may be important to keep most items in locked rooms, closets, cupboards, or drawers with only two or three items

available. For example, with only two or three pairs of underwear, shirts, dresses, or shoes accessible, there are fewer items for the person with dementia to mess up during the frequent searches. Also, extended searches through drawers and containers often build up stress and then anger both in the one searching and the caregiver.

Also, it helps to re-organize some household tasks. For example, picking up mail at a Post Office Box may be more reliable than delivery at the home mailbox or mail slot in the front door. Having two sets of trash receptacles can keep the real trash locked safely away from rummaging. The accessible trash cans available to the person with dementia should hold clean and safe trash and the caregiver should examine the contents routinely to check for valuables or “lost” items.

**Applying the Three-Step Cycle:** The caregiver should try to learn what sets off the repeated behaviors, such as rummaging. Perhaps the rummaging occurs at a specific time such as after mealtime, during the quiet of the afternoon when the person is bored, or later in the evening before bedtime.

A plan may involve setting up a couple of boxes or baskets of items for a person to look through in different areas of the house such as a basket of laundry to fold near the laundry room, a box in the family room of different pieces, textures, and designs of fabric to organize (by color or shape), a pile of magazines to move from one table to another, a box of newspapers containing coupons to cut out, a drawer of eating utensils (no knives) that need to be organized, a package of paper napkins to fold, a cupboard of plastic containers to stack or match-up with covers, etc. After each task is done, words of praise and appreciation should recognize the good work. Then the caregiver should discreetly mess up the items to ready them for the next time they are needed.

### *Disorientation*

As the person with dementia continues to decline, they may be unable to keep track of time and their location. Several minutes after eating, the person with dementia may ask, “When is lunch?” Any change in the setting such as new drapes, different colored towels in the bathroom, new paint on the walls, or moving the furniture around may be disorienting about the setting and lead to restless-

ness, pacing, or increased irritability. The disorientation may lead to passive acceptance as long as the loved one who regularly provides care is in sight.

A change in the caregiver, staff person, or family member (even a new outfit, eyeglasses, or hairdo) may lead to the sense of not knowing the caregiver and a general disorientation. The person with dementia may adjust after a while or may become disoriented, restless, and irritable. The change may lead to a feeling of being unsafe and an urgency to search for a familiar person or setting from decades before or their childhood. The reaction may show up as withdrawal.

When the person with dementia appears unsure of a caregiver's identity, the caregiver, mindful of validation therapy, should approach slowly, wear a pleasant facial expression, make eye contact, and use a label such as a simple name ("I am Ann your wife") or the role such as "I take care of you" or "I keep you clean," etc. Next orientation to time should occur in a meaningful way, such as the day of the week ("it is Monday"), the season ("it is winter, cold, and snowy outside"), what is done that day ("today is the day we dance to music"), an immediate function ("now it is breakfast time" or more simply "now it is time to eat"), or the here and now while looking out a window at daylight ("it is day time and you are eating").

Sometimes disorientation results from medicine which the person may have taken for a long while or just started. An adjustment in medicine should help.

**Applying the Three-Step Cycle:** The caregiver should try to learn the signs of the disorientation. These signs may be a confused or worried look on the face, the eyes shifting from person to person or from one object to another, not making eye contact with anyone, pulling away or walking away from anyone who talks to the person with dementia, or questions that indicate that the person with dementia is looking for a parent or someone else who no longer exists. If the surroundings are disturbing such as the room being too warm, the light too strong, or the noise too loud, the person may become disoriented and act out or refuse to cooperate or do a task.

Forming a plan should include steps that begin an interaction with simple orientation to time and place based on the language ability, especially the level of comprehension and short-term

memory of the person with dementia. Moving to a calmer setting may help. Each piece of information or changed action that helps to calm or comfort the person with dementia should lead to a reward such as a smile, praise, or other positive words from the caregiver.

### *Pacing, Wandering, and Missing*

Restless, repeated movements and pacing throughout or inside-outside the house and yard in safe areas can provide good exercise. It can also increase the person's anxiety and agitation. A restless, pacing person may go outdoors, wander off, and become missing. Sometimes the person with dementia who routinely stays in the yard, neighborhood, or walks the same outdoor route through the neighborhood every day becomes distracted or disoriented and then lost.

Many facilities such as ALFs (assisted living facilities) or nursing homes provide an alarm anklet for residents to alert staff when the resident exits inappropriately. Cell phone tracking systems are still being refined for accuracy and use at a reasonable distance.

The person with dementia who has wandered off once should be considered to be a risk to become lost. This person should wear some kind of identification such as name (first name) and phone (of a program not the person's home) labels sewn on all clothing, an identity bracelet or identity necklace with the person's first name and a contact phone number of a program, for example, the Safe Return program (now linked to the Medic-Alert program) of the national Alzheimer's Association, the Florida Silver Alert Program (several other states have Silver Alert programs), the Project Lifesaver program in some communities, or other appropriate organized identification program. Through these programs information about the person (and often a recent photo) is on file at a local or national office.

When someone meets a person who appears disoriented or lost, an identity bracelet or identity necklace may reveal a phone number of the resource office to call to return the lost person home.

When the person with dementia has driven a motor vehicle and not returned home when expected, after a brief search the caregiver or family member may report the person as missing by phoning (in Florida) the emergency number 911, which links to a law enforcement officer.

After taking a few details, the law enforcement officer decides about activating a Silver Alert search. Depending upon the resources in the community, a Silver Alert search may involve alerting a network of community law enforcement officers such as officers in patrol cars, notices in the public media, and a highway sign that displays an active message.

The current Florida Silver Alert Program applies to those lost while driving as well as people who become “lost on foot.” The Florida Department of Elder Affairs has sponsored the “Lost on Foot Project” to develop suggestions and ways to do the following:

- Search the immediate area where the missing person was last seen;
- Increase the search area; and
- Involve local law enforcement, for example phoning 911 to report the missing person.

In addition, several types of equipment, for example, GPS (Global Positioning System which uses a satellite system to locate people or places), cell phone triangulation, radio frequency identification, and other items are commercially available. Visit [www.floridasilveralert.com](http://www.floridasilveralert.com) for information on some of these items.

**Keeping current information handy:** Caregivers should keep a list of current, important information about the person with dementia in case the person ever becomes lost. Helpful are the following:

- Information about contact people including name, address, and phone number of the primary caregiver, physician, neighbor, etc.;
- A recent photo of the person;
- The names of a support network so that if a neighbor or person in the community sees the person with dementia outdoors away from home and alone, the caregiver or another contact person will be notified. (In rural Florida, law enforcement persons and community leaders often know everyone in the community and will readily drive such a person home.); and
- A closed plastic bag which holds at least one piece of clothing worn by the person and that has been handled with plastic gloves in case a rescue-dog is used to search for the missing

person. The clothing item should be replaced each month.

**Searching for a Missing Person:** As soon as a caregiver realizes that the person with dementia really is missing, even if it has been only 10 or 15 minutes, a search should begin. If the lost person is cognitively impaired (has Alzheimer’s disease or a related dementia), the caregiver should phone 911 immediately. The lost person may not call out for help or respond to people’s calls. The person may get stuck in a place that they cannot get out of, such as a closet, shed, culvert, ditch or creek, behind trash bins, or in a large section of tall bushes. They may wander into a lake and drown.

Research shows that often the missing person is close to home and not further than within a one-mile radius. If outdoors for too long, the person with dementia may suffer from high or low temperatures, dehydration, or falls resulting in scrapes or cuts which may become infected.<sup>9</sup>

The person with dementia may drive in a direction that is familiar or continue driving until the gas tank empties, after which they probably will walk on the road or by the side of the road until they tire. Then they may fall asleep in a ditch or clump of trees near the road but out of view.

If the person drove away, and has not returned home when expected or if the person is not supposed to be driving, the family should phone 911 (in Florida) to report the situation to law enforcement.

**Applying the Three-Step Cycle:** The caregiver should try to learn what sets off the pacing, wandering, or getting lost. The pacing may occur at a specific time such as after breakfast when the person was used to going through the house to do chores such as bed-making and laundry or leaving the home after breakfast to drive the car or take the bus to work. The pacing may occur when the person has a need such as thirst, hunger, full bladder, or feels pain.

The senses such as sight, hearing, or smell may be receiving pleasant or unpleasant information that may be triggering the pacing or restlessness. The following are examples of these triggers:

- Odors from detergents, aerosols, cologne, or food cooking;

- Noises from a T.V., music, the sound of yard equipment outside the window, or from people talking, crying, or moaning; and
- Lighting changes from outdoor or indoor lighting that is too bright or too dim, etc.

Perhaps boredom is the issue. A plan may involve setting up a schedule of exercise, time on a walking path in a secured area, leading a person to a secured outdoor patio or a setting that looks like a bus-stop. Other possibilities are time in a quiet room with interesting books and magazines or boxes of textured objects to handle. The plan may consider inviting a welcome visitor to come at the “trigger time.”

Setting up tasks that can be considered “work” may include a daily routine of activities such as making the bed, folding laundry, setting out plastic utensils and dishware, etc., for mealtimes, washing plastic dishes in the sink, watering outdoor plants, sweeping or raking outdoors, petting or brushing a pet, moving magazines from one table (or box or corner of a room) to another, etc.

When applying the steps of the plan, it is important to remember to work in rewards often to strengthen the positive behavior.

### *Angry Outbursts*

Triggers for an anger outburst may vary. Anger may grow from not understanding who people are or what they are saying. An unmet need may lead to anger, for example, thirst, hunger, a full bladder, an infection, boredom, and joint or other kind of pain. After an especially busy activity or weekend, fatigue for a couple of days after may lead to irritable or angry behaviors. Change such as a different caregiver, a new setting, traveling in a different vehicle, meeting a stranger, or wearing a new and different outfit may lead to an angry mood. Fear from seeing a large dog approach or from sudden loud outdoor noises may be triggers. For example, a screeching car tire, a roaring jet plane, a lawnmower, leaf blower, or thunder clap may set off an anger reaction.

If the person with dementia is unable to communicate about feelings, anger may be expressed in a look or behavior such as a serious or angry face, pacing, refusing to participate, using foul language, yelling, threatening gestures, picking up an object and throwing it, slamming a

door, or banging a fist against a table or other surface.

To avoid an anger outburst, a caregiver should learn what sets off such behavior and plan ahead, such as staying on a familiar schedule or using simple distractions. Strategies can help to catch the outburst before it starts or at the earliest signs of irritability. Responding to a physical need such as hunger or thirst on a regular schedule may help. Offer a snack or drink of water every two hours to ward off outbursts. Responding as soon as a need is evident such as seeing hands pulling at the groin area may be a sign to use the toilet. A person with dementia who is mouthing objects may be hungry. (Note that people with moderate or severe frontal lobe dementia may constantly put objects in their mouth.)

Sometimes a caregiver needs a brief break. Rather than reacting to an inappropriate behavior with a loud, “No!” or “Stop!” or yelling at the person with dementia, it is much better to give both the caregiver and care receiver a 10 minute “time out.” If the person with dementia is in a safe setting, time to act out the anger alone may help. Throwing pillows around or banging on plastic objects may help to channel the anger. The caregiver could say, “I want a drink of water. I’ll be right back,” and switch on soothing music on the way out the door. Being left alone may offer enough change to stop the anger outburst.

The break can give the caregiver time to relax, refresh, and remember that the anger springs from the dementia. The time out allows the caregiver to think about the attempted task that may have started the anger outburst. Then the caregiver can return to the person with dementia and approach the task a new way such as doing only one or two steps of the task now and then later the rest of the task. Bringing in another person may work. Sometimes the best approach is to switch to a different activity that the person with dementia enjoys.

**Applying the Three-Step Cycle:** The caregiver should try to learn the beginning signs of anger. During the whole episode of anger, the caregiver must remain calm within and without, more specifically in body language such as showing a smiling face, a relaxed, positive posture, and using a pleasant voice.

If the angry behavior relates to fatigue after a busy day, then the caregiver should try to schedule more rest times and shift important tasks to the morning. If the anger reaction relates to a spe-

cific task such as bathing, then breaking the task into small steps should help. While a full bath or shower is not needed every day, a frequent daily sponge bath can clean soiled areas that need attention. After each successful step, that step should become part of the routine procedure for doing that task. After each unsuccessful step, the caregiver should try a different approach. After each step of the task is done, words of praise and appreciation should recognize the good job.

For example, if the person refuses to undress for a bath, the person may tolerate first taking off shoes and socks for a small reward, then the pants, etc. In another approach, the person with dementia could wear a special shower gown that opens at the shoulders and back. If the person undresses, but wants to dress immediately, the clothes that came off should be whisked out of sight as soon as they are off. The person should be given something to distract them such as a waterproof book, a fancy bath mitt, a big sponge to squeeze, or a glass of a small amount of beverage. Bath time may work with two people, one person talking to or singing to the person with dementia as the other person washes. Rewards such as enthusiastic words of praise should compliment everyone involved.

## Sleep Difficulties

People with progressive dementia often have problems with their sleep-wake cycle. Sleep problems become worse when people nap, which takes the edge off their “sleep hunger.” Sleep hunger refers to being tired and eager as well as ready for a night of good sleep. Exercise during the day helps to build sleep hunger.

Sometimes people will sleep well through their first cycle of sleep, which typically lasts 90 minutes but not well afterwards. Some will sleep well through their first two cycles of sleep, about three hours. After that, the sleep is restless or if they wake up to use the bathroom, it becomes hard for them to fall asleep again.

People who need a nap and have trouble sleeping well at night should not nap after 2 p.m. or 3 p.m. People should not sleep more than a total of 14 hours over a 24-hour period unless there is a specific reason for doing so such as recovering from an illness or surgery.

Sleep hygiene involves managing the activities and setting for quality sleep. When good sleep occurs, the person awakens feeling rested. Sleep hygiene is important for the person receiving care and the caregiver and is discussed next.

Limited caffeine after 12 noon and no heavy bedtime snacks may help sleep. Taking a few hours to relax before bedtime, doing relaxing activities, and drinking some warm milk (a source of melatonin) may help. Bedtime is the time to relax, not the time to discuss or think about stimulating topics. In other words, relaxing before bedtime means minimal excitement such as no lively scary movies, mystery programs, negative television news, or exciting books; no bill paying; no arguing; and no discussions of major worries such as the state of the economy, national crises, or terminal illnesses. Such rousing activities should occur early in the day, not in the one to two hours before bedtime.

People should learn about individual differences that relax people and lead to good sleep. A warm bath and backrub before sleep relaxes some people and energizes others. The bed should be comfortable with no noise in the bedroom. The bedroom temperature should be a little cooler at night. Several pillows may be important to raise the person’s head to help breathing. People with sleep apnea should use their equipment faithfully. While the bedroom should be dark, a dim night light in the corner of the room or in the hall can prevent tripping during short nighttime visits to the bathroom.

Sleeping with a pet may help some people to relax and others to be restless. If a pet dog snores and disturbs the person’s sleep, the dog should sleep in a different room. If the cat typically sleeps on the person’s bed and the purrs and twitches disturb the person’s sleep, the cat should sleep in a different place or room.

When the person with dementia sleeps well at home, the family caregiver sleeps well. When the person with dementia in a facility sleeps well, the night staff has more time to take better care of everyone at the facility.

**Applying the Three-Step Cycle:** The caregiver should try to learn the pattern of the sleep problem, bedtime activities and preparations, and how many naps as well as cat-naps the person is taking. This information is important to create a plan for good sleep hygiene.

The sleep hygiene plan should consider setting up a routine that considers the activities of the person with dementia during the 24 hours of the day. For each successful step toward good sleep, a special reward should be provided in addition to the benefit of the person with dementia and the caregiver feeling rested when they awaken.

### *Hallucinations, Delusions, and Misperceptions*

Hallucinations and/or delusions may occur as a result of brain cell changes in various types of progressive dementia.

Hallucinations may involve the five senses (sight, hearing, taste, smell, or touch). Typically in Alzheimer's disease and related disorders hallucinations involve seeing images (people, animals, or objects) or hearing sounds (words, conversations, music, or other sounds) that are not there.

Sometimes the images are misperceptions. In other words, the person with the dementia does not accurately understand the image because of brain cell changes. For example, dim light, shadows, reflections; patterns on wallpaper, linen, or clothing; or images on television may be distorted or misinterpreted. Shiny surfaces such as mirrors, glossy metal surfaces, or shiny, polished furniture may distort reflections that are perceived as scary strangers or hurtful people.

Delusions may involve distorted ideas and false beliefs such as believing that family members are trying to hurt you or that a neighbor has stolen and is driving your car.

An early sign of Lewy body dementia often is visual hallucinations, typically people or animals which are seen but are not there. Occasionally the hallucinations are words or music that are not real. Sometimes people with Frontal Dementia and with moderate or severe Alzheimer's disease may have hallucinations and/or delusions.

When the hallucinations occur early on in the course of the dementia, the person often knows that the images or sounds are not real and may not be upset by them though the family caregiver may be upset. Understanding that the hallucination is a result of mixed up brain signals from brain cell changes often helps people to adjust to and accept the hallucinations.

Sometimes later in the course of dementia, the hallucination may distract or provide pleasant company for the person with dementia, especially with positive experiences such as seeing a nice pet, a friend from long ago, or a small group of pleasant children.

When the hallucinations are images of threatening strangers or robbers which become quite upsetting, the caregiver should try to observe what triggers the hallucination, form a plan to change the reaction, and act on the plan. For example, if the fearful behavior occurs whenever the person looks in the mirror, first the caregiver should remind the person with dementia ("I am your wife, Ann," or "I am Joe. I help you," or "I keep you safe"). Next the caregiver should cover or remove the mirror. Then the caregiver should comfort the person with dementia, begin to redirect them to a different room or activity, and then offer a reward such as a snack or a fun activity such as listening to favorite music or going for a ride in the car.

If the fearful behavior occurs at night, learn whether it occurs when the person with dementia looks at a specific object such as a huge armchair in the bedroom. The plan to cover the chair with a bright, plain sheet, or other cover may work. If not, the chair should be removed from the house. Rather than insisting that the person is not seeing anything that is really there, it is better to be sensitive to the person's feelings and to cover or remove the offending item. Empathic responses, as discussed in Validation Therapy, allow the person to feel heard and the feelings respected. Successful steps of the plan should receive a reward such as kind, comforting words. For example, it may increase the person's comfort level to walk through the house with the lights on, visit the toilet, return to bed (with a nightlight in the nearby hall or bathroom), and receive words of appreciation for handling things so well.

**Applying the Three-Step Cycle:** The caregiver should observe any signs of a frightening or negative hallucination in the person with dementia. Retracing the path or activities that occurred before the signs occurred may uncover a piece of furniture, photo, picture, or plant that should be covered, moved to the corner of the room or removed completely from the house. Better lighting in the house, especially at sunrise or sunset may help.

As part of the problem-solving plan, if the person with dementia can bring the caregiver to the spot where the hallucination occurs, the caregiver can soothe the person with dementia, and then fix the problem area such as covering a bothersome area and afterwards taking the person with dementia into a setting that provides the reward of pleasant sensory stimuli. During the day a reward may be a piece of fresh fruit, listening to a favorite song, counting gold fish in an aquarium, spending time with others, or sitting on the porch and watching the activity at the bird bath for a while.

### *Maintaining Nutrition*

A good diet and good intake of fluid are important to keep up with daily good nutrition. People with moderate or severe Alzheimer's disease may forget to eat. Healthy teeth and gums are important for good nutrition. Some refuse to eat more than a few bites or drink a few sips at a time. Even those who eat well lose weight.

The loss of the sense of smell or taste may result in less interest in eating. A good sense of smell is important to the actual taste of food. People who have damage in the nerves that send smell and taste information to the brain and the brain cells that interpret those signals may complain that the food is tasteless. Brain cell changes may impact the ability to bite, chew, and swallow food efficiently.

Some people with moderate and severe Frontal Dementia have the opposite problem, an unusual hunger for sweets or eating constantly. More activities in the daily schedule may help to distract them. For people who insist on eating too many sweets, providing well-balanced meals with protein and complex carbohydrates, such as whole wheat bread, brown rice, oatmeal, and barley, and fresh fruits may help their sweet tooth and modify their weight gain.

Regular daily exercise may stimulate the appetite. The food should feel comfortable in the mouth, not too hot or too cold. Adding different textures to the foods served at mealtime may help. Offering different foods of different colors may help. Colorful dishes and napkins may stimulate the appetite.

Talking about the taste and smell of foods in positive terms and linking the food to past memories of enjoying that food may help the person with dementia to recall previous enjoyment of that food. Thus the recall may

compensate for the actual, current flat flavor of that food.

For people with vision-perception problems, the color of the food should differ from the colors of the dishes to help them see the food as different from the background of the dish. Also, the napkins and table surface should be different colors.

When feeding people, one small spoonful at a time will help them to not choke. The mouth should be empty before the next offered spoonful. The person with dementia may benefit from reminders to chew and swallow. If before the next spoonful of food, there is any sign of swallowing problems, a reminder to swallow, cough, and swallow again may help. The person with dementia should sit upright at meal times and for at least 30 minutes after eating to avoid choking. If the person is unable to handle solid pieces of foods, smooth foods may work. If the person is unable to handle smooth foods, liquids may work.

A straw or "sipping" cup may help with drinking beverages.

**Applying the Three-Step Cycle:** The caregiver should try to learn the series of actions leading to a loss or gain of weight. If the person with dementia complains that food has lost its smell or taste or hurts when chewing, a medical and dental evaluation may solve the problem. A referral to a dietician may help. The plan to improve nutrition may include smaller, more frequent meals, handy nutritious snacks such as pieces of cheese and soft, colorful fruits ready to eat on the kitchen table during the day, foods of different colors and textures at mealtime, and mealtime stories that recall fun gatherings with special flavorful, enjoyed foods.

During mealtime struggles, the caregiver must remain calm with calm, pleasant body language such as showing a smiling face, a relaxed, positive posture, and a nice voice. The plan may include trying to link with one or more other people, which may stimulate the appetite. Soothing music in the background may help. However, some people may find it too distracting to focus on eating when they are eating with others and prefer to eat alone in a quiet setting. Praise and an enjoyable activity after the meal may reward good eating behavior.

## Summary

Throughout the stages of decline in Alzheimer's disease and related disorders caregivers face many behavioral challenges. Strategies to help the person with progressive dementia to function well include using memory helps, keeping on regular daily and weekly routines, and breaking down tasks into simple steps. As abilities decline, the person with dementia may become increasingly frustrated or angry with the changes.

Validation Therapy offers a gentle, empathic, positive way for caregivers to approach and interact with people who have progressive dementia during such difficult times. Validation Therapy:

- Responds to the emotion of the person with dementia by reflecting the person's feelings with gentle, soothing words and actions.
- Slowly moves the attention of the person with dementia who is showing frustration or irritation to a safe, new direction, topic, or setting.

Combining the principles and techniques of Validation Therapy with the Three-Step Cycle for solving problems can help caregivers deal with many challenges. The three points of the Three-Step Cycle consist of:

1. **LEARN:** Understand the disease and related behavior changes, and observe to learn what starts the behavior problem in the person receiving care. In other words, learn.
2. **PLAN:** Think of a new method to handle the task or activity and to avoid starting the problem behavior. Break down the method into the smallest steps possible and match each successful step with a reward. In other words, plan.
3. **ACT:** Try out the steps of the plan. Reward the care receiver for each successful step. Then reward yourself. If a step of the plan does not work, rework the plan and try again. In other words, act.

Some of the challenges involved in long-term care management that may benefit from the Three-Step Cycle include the following:

- Repetitive behaviors;
- Disorientation;

- Pacing, wandering, and getting lost;
- Anger outbursts;
- Sleep difficulties;
- Hallucinations, delusions, and misperceptions; and
- Maintaining good nutrition.

The following lists ideas for rewarding successful steps toward appropriate and healthy behaviors:

### Ideas for Rewards

**Positive subjects to discuss:** any favorite subject of person; family, religious or national holidays; favorite colors; former career; former or current hobbies, sports

**Pictures to discuss:** relatives, babies, actors and actresses (from years ago), historical leaders, art, pets, birds and other animals, weddings, pocket watches and old clocks, landscapes, farm fields, and gardens

**Pictures or picture books of:** antique cars, street cars, a horse and buggy, and fashion from decades ago

**Snacks:** healthy foods and beverages

#### Sensory Stimulation:

- rich colors, especially the primary colors;
- listening to soothing music to relax or stimulating music to increase energy
- touching different textures of fabric, squeeze balls (firm or foam balls), dishpans of warm or cool water holding objects of different textures;
- taste and smell: foods or liquids of different favorable tastes and odors such as vanilla, chocolate, peppermint, cinnamon, lavender and other flower odors, oregano, cumin, air fresheners or colognes, after-shave lotion

**Exercise:** walking, walking the dog, swimming, water aerobics, chair exercise, dancing, exercise to music, gentle massage on the arms, face, shoulders

**Music:** music with or without words to listen to or sing along with, hand instruments for group music

## Related Websites

Administration on Aging  
Washington, DC 20201  
1-202-619-0724  
[www.aoa.gov](http://www.aoa.gov)

Alzheimer's Association  
225 North Michigan Avenue, 17th Floor  
Chicago, IL 60601  
1-800-272-3900  
[www.alz.org](http://www.alz.org)

Alzheimer's Disease Education and Referral Center  
(ADEAR)  
PO Box 8250  
Silver Spring, MD 20907  
1-800-438-4380  
[www.alzheimers.org](http://www.alzheimers.org)

Alzheimer's Foundation of America (AFA)  
322 8th Avenue, 7th Floor  
New York, NY 10001  
1-866-AFA-8484 (1-866-232-8484)  
[www.alzfdn.org](http://www.alzfdn.org)  
[www.alzquilt.org](http://www.alzquilt.org) (a quilt to remember)

National Family Caregivers Association (NFCFA)  
10400 Connecticut Ave, Suite #500  
Kensington, MD 20895  
1-800-896-3650  
[www.nfcacares.org](http://www.nfcacares.org)

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8. DeKlerk-Rubin, V. (2007). *Validation Techniques for Dementia Care: The Family Caregiver's Guide to Improving Communication*. Baltimore, MD: Health Professions Press.
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# Chapter 13: Activities for You & Your Loved One

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## **Purpose**

To introduce principles to help guide the best choices for activities and help to approach such activities for the most satisfaction.

## **Objectives**

Upon completion of this session, individuals will be able to do the following:

- Understand six principles when planning for and doing activities with someone who has Alzheimer's disease or a related dementia.
- Learn about some activities that offer exercise, social interaction, and positive experiences.
- Assist with eating, bathing, dressing, walking, sleeping, and toileting.

## **General Principles**

It is generally believed that a variety of activities and social interactions can provide cognitive stimulation. Activities offer moments of change from the daily schedule and relief from boredom. Brain stimulation from the activities helps people with dementia to function at their best and enjoy the highest possible quality of life – both for themselves and their loved ones. Caregivers should consider the following six basic principles when planning activities.

### **Six Basic Principles**

1. Enjoy the Activities.

*Remember*, dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

2. Relate Activities to Lifelong Interests and Abilities.
3. Family Members, Friends, and Caregivers Should Initiate Activities.
4. Focus on the Senses (Sight, Sound, Smell, Taste & Touch).
5. Focus on the Here and Now.
6. Keep It Short.

### **First Principle: Enjoy the Activities**

The first and most important principle is to choose activities that are enjoyable for all involved. This is important for a few reasons. One important reason is that persons are usually most motivated to pursue activities that they enjoy. On the other hand, they are likely to spend little to no time doing activities they do not enjoy or always disliked. Further, stress and irritability can actually interfere with cognitive processing (the thinking work of the brain) and therefore, undermine the benefits of activities.

Any activity should be discontinued if it results in anything beyond mild frustration.

### **Second Principle: Relate Activities to Lifelong Interests and Abilities**

A second important principle is to choose activities that draw on the long-term interests and abilities of the person with a progressive dementia. Once persons have been diagnosed with dementia, such as Alzheimer's disease or a related disorder, they can be expected to develop serious difficulties learning new information. Learning new activities may be extra hard and frustrating for them (and the caregiver). Therefore, new learning activities should

be very carefully chosen on the basis of their importance and how they relate to everyday functioning. Focusing on long-standing interests and abilities will enable persons with progressive dementia to use and exercise their minds in constructive ways without creating too much frustration and stress.

### *Third Principle: Family, Friends, and Caregivers Should Initiate Activities*

The third general principle is that family members and friends should assume the responsibility to plan, set up, start, lead, and finish the steps of the activity. Frequently, one of the symptoms of progressive dementia is loss of ability to plan a task or activity, to start it, and then to stop when done. Persons with progressive dementia will simply not think of ideas for things to do. They may not be able to pursue the activities on their own. However, if someone else helps them to choose an activity and helps to get it started, the person with progressive dementia can join in and have a great time.

### *Fourth Principle: Focus on the Senses (Sight, Sound, Smell, Taste & Touch)*

Activities which focus on the senses – sight, sound, smell, taste, and touch – tend to be very successful. This principle is true because the objects and activities which stimulate the senses provide a real, accessible experience. The experience offers persons with dementia an anchor around which to focus attention and conversation. They do not have to use their imagination or memory in order to keep it in mind. The experience happens in an actual physical way. For example, taking a walk in a park and discussing the sights and sounds along the way is easier than joining a conversation of people discussing their recent experiences about seeing a garden or smelling fragrant roses. Having the rose to smell, here and now, makes the experience real and accessible for reflection and conversation.

### *Fifth Principle: Focus on the Here and Now*

Persons with moderate or severe Alzheimer's or related disorders will have trouble holding in mind remarks that were made in the beginning of a conversation. They may be unable to remember what happened an hour, 30 minutes, or five minutes earlier. Therefore, the topic and names of people should be repeated often in order for the person with dementia to keep up with the conversation and to make related comments. Details of events that occurred a while ago and are being discussed now should be re-

peated especially with reminders about when the event happened to keep the person oriented. It is best to talk about and focus on what is occurring right now.

### *Sixth Principle: Keep It Short*

It is important to allow enough time to interest the persons with dementia and to bring them into the activity. But keep activities brief in order to avoid overly tiring them. Fatigue adds to the risk of building up frustration, irritability, or lack of cooperation in people with dementia.

## **Activity Suggestions**

Back to a recap of the first principle: keep it light and fun, not stressful! Well-meaning loved ones often push persons with dementia to pursue activities on the grounds that it will be “good for them.” Further, loved ones or other caregivers tend to assume the role of teacher or monitor, rather than partner or friend during an activity. While they intend to be helpful, this approach is often experienced as stressful and demeaning to persons with dementia, and so they will quickly want to stop the activity. Anxiety and depression can actually make memory problems worse and make this approach backfire. If you can find a way to make activities fun, they may benefit the quality of life for everyone!

### *Playing Games*

Playing Games is often recommended as a source of cognitive (thinking) stimulation (also called brain exercise). Indeed, games cause us to draw on many of our cognitive skills. Familiar games may stir up memories from long ago. Sharing these memories with the others in the group may add to the fun.

Below are a few guidelines to make game-playing fun and constructive for persons with dementia:

- Choose games that are familiar (Scrabble, cards, dominoes) and reduce the game to simpler steps as needed. For example, make a larger Scrabble board, increase the number of letters and remove the letters such as Q, X, or Z which are hard to use to form words. In another example, use larger playing cards, and play games learned in childhood such as matching pairs of numbers or like designs (diamonds or hearts). Bingo cards with large letters and numbers are fun when Cheerios or other cereal, M&Ms, or small marshmallows are used to mark the squares.

As noted before, persons with progressive dementia will likely have great difficulty learning new games. However, the games they already know will provide plenty of brain stimulation.

- Feel free to change or adapt rules that are too difficult. Playing in teams may work better than playing as individuals. Changing rules also involves a different approach to adding up or keeping score. One way to keep score is for a success from either team (or player) to provide a point for each team (or player). Play just for the fun of it!
- Don't allow game-playing to become a test! The stimulation of "playing" and being together with others is more important than "getting it right" or winning.
- Tossing the balloon or (large) soft ball can be a lot of fun. Using different colored balloons and calling out the color when the balloon is hit adds language exercise.

### *Music*

Music is a powerful source of entertainment and can also be used to help change a person's mood. Have tapes/CDs/videos available with long-standing favorites – by favorite performers. These favorites can always be used to "fall back on" when no other activities are readily available – like on a rainy day.

Play soothing music when the situation calls for a calming effect; play up-beat music when the situation calls for building up energy; play light music for lighting up the mood. Music should not be too loud or have too much bass which may make people irritable and hurt sensitive ear drums. Singing along can be great fun! Music can also be used as a great starter for reminiscing and conversation. For example, "Remember when we went to hear..."

### *Short Movies/Plays/TV Programs*

Persons with dementia will have difficulty with anything that involves a long storyline or plot which is important to remember from the beginning in order to appreciate the ending. Therefore, avoid dramas and mysteries. Rather, choose comedies and musicals – things that can be enjoyed from moment to moment. The History Channel on T.V. and nature shows that are not too violent can be enjoyable – depending on the person's long-standing interests and knowledge.

Re-watching old favorites can be very enjoyable. People with memory problems often enjoy seeing the same program over and over – it seems new and fresh each time.

### *Outings*

All kinds of outings can be mutually enjoyable for persons with dementia, their friends and families. The principle of drawing on long-standing interests usually applies here, as does the principle of focusing on the senses. Below is a list of just a few outings:

- Sporting events in small parks or stadiums that are not too large or high
- Art exhibits
- Visits to the library
- Drives or walks at the beach or lakeside
- People watching at a park or mall – particularly where children are playing
- Exercise classes
- Bird watching
- Shell collecting
- Restaurants – choose a restaurant with a relatively quiet setting where conversation is easily heard and understood. Interesting décor or atmosphere can help stimulate conversation. If easily over-stimulated, the person with dementia may need to sit facing an area with the least amount of activity, not facing the kitchen, the center of the restaurant where people are coming and going, and not facing the parking lot. The person with dementia will likely need some assistance with ordering from a menu. Friends or family can help by narrowing the choices and suggesting one or two known favorites. Also, have the food cut up into small, manageable pieces before the food for the person with dementia is brought to the table.

### *Household Activities*

During the course of the decline, persons with dementia will begin to have difficulty with long-standing household responsibilities and tasks. For example, a person who has always been responsible for paying the bills will begin to make unacceptable mistakes. However, persons with progressive dementia often want to continue contributing to the activities of the household. So, creatively reassign-

ing or adapting their duties can allow them to remain active and productive. Feeling productive and useful helps to boost self-esteem. Doing tasks also exercises the brain cells.

In the earliest stages of dementia, a person may still be able to pay bills and record checks. However, an adaptation might be to allow a family member (or significant other) to “double check” the math and the fine details of the work. Teaming up to complete a task may help.

Below are activities that often can be continued for a very long time:

- folding laundry, like linens or t-shirts;
- kitchen duties – setting and clearing the table for a meal, putting dishes in the dishwasher, putting dishes away, or washing fruits and vegetables;
- making beds;
- shining shoes;
- arranging flowers;
- watering plants outdoors such as in the garden;
- sweeping the porch and sidewalks;
- dusting;
- polishing counter tops, furniture or silver;
- sorting coins or large buttons;
- organizing eating utensils (not knives);
- washing porch furniture;
- washing and waxing the car; and
- using sandpaper to smooth old furniture or blocks of wood.

### *Reminiscing*

Reminiscing draws on long-term memories and can be an immense source of pleasure for all parties involved. Persons with dementia are often able to tell stories of their early life experiences that are interesting and entertaining. They may also be sources of wisdom and important life lessons that can be passed along to younger generations. The birthday of an individual or everyone born in the same month may be fun to celebrate. Below is a list of materials that can start people “remembering when...”

- Family photo albums – look through the album or make an album together and start the conversation about the pictures by recalling details to help trigger memories. This is not the time for a “quiz,” so avoid asking, “Do you remember who that is (or where that is)?”

Instead while pointing to the picture give information such as, “We had fun swimming at Lake Toby with my brother Joe and our dog Sam. Look at how they are splashing in that cold Lake Toby water.”

- Picture books, catalogs, and magazines of all kinds – especially those with older or historical material;
- Old picture calendars; and
- Antique/Period clothes, jewelry, shoes, hats

## **Summary**

While persons with progressive dementia struggle with certain cognitive problems (such as short term memory loss and recalling words) that result in difficulties with many of their activities of daily living, they may still be able to do many other tasks and activities. Look for the abilities that remain and help people to use these skills as a way of keeping them as strong as possible. Even if activities are forgotten later, the fact of having done them at all can provide great enjoyment “in the moment” for all involved. This enjoyment can improve mood and stimulate the brain in a positive way, even if later they cannot recall the details of the activity.

Lastly, remember that people with progressive dementia keep a great capacity for love, laughter, and the enjoyment of “simple things in life” – which are often the ones valued most in the end by all of us.

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Kennard, C. *50 Activity Ideas for Someone with Alzheimer's*. [www.alzheimers.about.com/od/frustration/a/50ideas.htm](http://www.alzheimers.about.com/od/frustration/a/50ideas.htm) ([www.About.com](http://www.About.com) Guide to Family Crafts; 150 Simple and Fun Projects Everyone Can Make Together)

Dixon, C.C. *Activities for People with Alzheimer's*, [www.recreationtherapy.com/tx/txalz.htm](http://www.recreationtherapy.com/tx/txalz.htm).  
[www.activitytherapy.com](http://www.activitytherapy.com)



# Chapter 14: Family Issues

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## **Purpose**

To assist health care providers to understand issues that affect both the family and caregivers of people with Alzheimer's disease and related dementias and to develop strategies for successful interaction with family members.

## **Objectives**

Upon completion of this session, individuals will do the following:

- Identify attitudes and feelings about caregiving that can affect interactions and caregiving activities.
- Learn about common family issues and ways to address these concerns.
- Identify states of grief and ways to help.
- Identify stressors and ways to reduce stress.
- Understand the meaning of role reversal.

## **Attitudes and Feelings About Caregiving**

To understand the attitudes about caregiving, a person must accept the fact that Alzheimer's disease and related dementias (AD) are progressive illnesses resulting in changes in physical and cognitive (thinking) abilities over time. Despite the best efforts by health care providers and support from families, it is difficult to cope with the fact that the health of the care receiver will continue to decline. This decline can lead to a sense of frustration because the caregiver cannot control the changes brought on by the illness.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

## **Tips and Techniques**

To meet the challenges of caregiving, it is important to remain supportive and understanding to the person with AD and at the same time keep in mind the changes that the illness brings. Sometimes it can be difficult to separate the person from the illness. It is helpful to focus on the special qualities of the individual such as their love of the following: nature (they may love to refill the bird feeder), ice cream especially chocolate, and waxing the car. The caregiver should enjoy the unique personality of the loved one who has AD. Remembering their preferences can help keep the daily routine interesting and a positive experience for everyone involved. Try to keep a sense of humor and enjoy each moment.

## **Emotional Distance**

Maintain a healthy emotional distance. Remember that the person receiving care is not responsible for his or her health changes. Emotional distance means that the caregiver should be more objective and set aside personal needs and feelings for a while in order to focus on a specific task. Emotional distance is especially helpful during difficult tasks such as bathing and toileting.

Being objective during difficult or tiring tasks allows the caregiver to focus more on making decisions that fit the needs of the moment and prioritizing care tasks. It also helps the caregiver to communicate respectfully and firmly about priorities such as the need to complete an immediate task (for example, to finish bathing) before going on to another activity (for example, going outdoors to watch the birds at the bird feeder). This approach can help a caregiver to remain focused on the steps required to complete a specific task.

Health care providers who respect their own healthy limits and use emotional distance may find that caregiving becomes less draining emotionally and more effective over the long term. Completing necessary or unpleasant tasks with an objective, can-do attitude can lead to more relaxing activities such as walking or spending time with friends in a small group activity.

### *Ongoing Support Important*

Family and other caregivers should support one another by taking time to affirm each other. They should listen when other caregivers have difficult or sad experiences. Frequently the best advice will come from another family caregiver or co-worker (in a program or facility) who has dealt with a similar situation. Finding someone to listen after you have gone through a difficult experience will reaffirm that you have good skills, demonstrated good judgment, and successfully tackled a difficult challenge. If you find that you are the listener, remind the family caregiver or your co-worker that they are also a valued member of a team with an important mission. Support from an understanding listener seems to build up energy in both people.

### *Anticipating and Planning Ahead*

When caregivers understand that people with AD and related dementias experience ongoing changes in their need for assistance, a dip in the AD person's ability to function will not come as a surprise. Family and paid caregivers should update each other on a regular basis about the abilities, preferences, and special tips that help the person with AD. As a result, the caregivers will be able to expect the simpler level of functioning, plan for the right kind of activities, and meet realistic expectations. Then the caregivers and the person with AD can enjoy small successes at the simpler level of functioning.

### *Involving People in Their Own Care*

Listen to people receiving care and try to involve them in conversations about their care, their former hobbies or work-life, objects in the room, past memories, or any topic that seems to spark interest. Share humor! The human need to interact and communicate daily is important to all. Interacting with people while providing care restores energy and well-being in both the care provider and care receiver. Family members will also have a brighter outlook if they see that their loved one is happy. Staying positive is important for all concerned.

## **Common Family Issues**

Families of people who have been diagnosed with AD and related dementias must face a number of difficult decisions throughout the progress of the disease. Most families will want to keep their relative at home for as long as possible. Family members may think that using a long-term care facility such as an assisted living facility or a nursing home is a "failure" to care for their loved one or to meet their responsibilities to their loved one. The family members may feel guilty and angry about such a change. Guilt can lead to anger and embarrassment, and these feelings may cause a family member to pass their feelings over to the health care providers and other staff members at the facility. A family member may show anger, frustration, or other negative feelings. These actions may be connected to other factors such as the following:

1. Previous promises
2. Isolation
3. Family conflicts
4. Unlearned skills
5. Unrelated problems
6. Showing feelings

The following paragraphs discuss the above six points in more detail.

### *Previous Promises*

Perhaps early in a marriage a promise was made to "never place a spouse in a nursing home regardless of what happens." These promises are usually made when people are young, healthy, and frequently just starting out on a life path. These promises may be unrealistic when a family caregiver is frail with arthritis, heart problems, or other health conditions later in life. A family caregiver may need reassurance that the health and well-being of each person in the family are important. The decision to provide hands-on care must address as much as possible the needs of all the family members. Holding onto a promise that is overwhelming the physical or emotional health of the caregiver may threaten the health and survival of the family caregiver and/or the family unit (the rest of the family).

### *Isolation*

Family members may feel trapped and alone in providing

care. A family caregiver such as an adult child (or grandchild) may be handling the whole household and now find that they are responsible for also handling their parents' household. Responsibility for two households causes not only financial strain but also time pressures and emotional strains. Frequently other relatives or friends may stop visiting or telephoning to avoid facing the additional demands for help from others. For some family members and friends, it is difficult to face the declining health of a loved one, and they may react by staying away.

### *Family Conflicts*

There may be long-term conflicts in a family resulting from unresolved issues from long ago. These issues may still carry strong feelings that rise up often whenever interactions occur with family members. Intense feelings, such as distress from seeing the decline in the loved one who has AD, may also hurt good interactions between the family and others outside the family.

### *Unlearned Skills*

Family members may have never learned how to work well together. They may not feel comfortable in each other's presence. Individuals may not know how to listen well and talk clearly to each other. They may not know how to match communication strategies to the needs of the different relatives. If a family did not work well together before a major illness, often it is more difficult for them to set their differences aside when a crisis appears. They may not be able to develop emotional distance, discussed before, in order to work with the family to plan, make needed decisions, and help in other ways to care for the loved one with AD.

### *Unrelated Problems*

Individuals within a family may be dealing with difficult situations that are totally separate from the illness. Family members may be under stress or in crisis from a situation such as unemployment, divorce, or their own illness. Frequently a health care provider can achieve better communication with a family by understanding who in the family is the main communicator and decision maker. Those responsibilities may lie within one respected older family member or shared by a few family members.

### *Feelings*

A family member may feel guilty about using volunteers or hiring companions to assist even when their relative who has AD is still at home. They feel even guiltier rely-

ing on a long-term care facility such as a dementia-specific assisted living facility or a skilled nursing home to provide constant care and supervision.

Feelings of guilt in a family member may also result from their own sense of failure. No matter how hard the family member worked or tried day after day to provide the best care for their relative, they could not slow down the progress of the AD and the care needs associated with the decline, such as frequent reminders to drink liquids or to do a task.

Also within a family there are underlying issues. When an adult child cares for a parent, it is possible that the parent may not have been warm and nurturing years ago when the adult child needed support as a youth. Even in a long standing marriage, there may be unpleasant issues that have been ignored.

Sometimes family members act demanding or hostile toward staff who provide health care in a day care center, assisted living facility, rehab center, or nursing home. They may complain about small details, appear never satisfied with the best efforts of staff, and make humiliating remarks about the care, the facility, and the staff.

## **Helping the Family**

Health care staff and other caregivers should communicate with family members respectfully, patiently, and with as much compassion as possible within health privacy HIPAA\* guidelines. Empathizing with the family to show support may be helpful to some degree. However, while health care helpers may recognize the difficulties families face, no one can understand how overwhelming AD can be to a family. Acknowledging that a family probably did everything possible before accepting assistance or placement in a facility often can help a family member to feel valued. Reinforcement and reassurance may also lessen guilt about using resources outside of the immediate family.

\*[HIPAA: the Health Insurance Portability and Accountability Act of the U.S. Congress, 1996, established procedures to protect the privacy of health information of people. In summary, HIPAA demands that health, social and other service providers only reveal identifying information (such as name, address, Social Security number, and date of birth) about people who need or receive health and related services to providers who are directly involved in giving direct care or services and to people whom the

care-receiver selects. People with a diagnosis of Alzheimer's disease or related disorders should identify early in the course of the disease at least one person to whom such private information may be revealed. (U.S. Department of Health & Human Services. Health Information Privacy. [www.hhs.gov](http://www.hhs.gov), accessed 9/15/11)]

Health care providers are also caregivers who enter a partnership with family caregivers to create and fulfill a care plan. Family caregivers will continue to experience burdens associated with their relative's illness and needs. The family with guidance from a physician ultimately carries the responsibility for making health care decisions for their relative.

Feelings of grief may be overwhelming to some family members. A family may require supportive listening and should be encouraged to participate in a support group related to their needs. Addressing the feelings of family members, recognizing their struggles with the situation, and being as objective and as specific as possible may help identify areas to improve care. Once feelings have been addressed, it will be easier to concentrate on care decisions.

## Loss

While difficult to handle and almost always unwelcome, loss is a natural part of life. When people relocate to a new town, they feel loss until they establish new routines and relationships. People who are ill grieve the loss of their health, independence, and previous abilities. People who have been diagnosed with AD or related dementias and their families must deal with the ongoing loss of memories and skills. This process may seem overwhelming as the decline progresses.

### *Grief at the Time of Diagnosis*

The grief that comes with a diagnosis of AD or related dementia is only the beginning of continued change and additional grieving in the years to come. The person with AD will lose memories and skills. At the same time family members slowly lose the person they knew before the decline of the disease. AD and related dementias require adjustments by everyone.

Sometimes the adjustments seem never-ending and overwhelming. With AD memory may be the first ability that is lost. Next may be a decline in the ability to recall names of people and other words as well as some other language skills. Then thinking skills weaken and finally the basic

skills of everyday life, such as feeding and dressing oneself are affected. Other related dementias may present first with a loss of ability other than memory such as initially a change in walking or in personality.

A family will miss the ability of the person with the dementia being able to think quickly and plan together with others. Lost will be the ability to exchange deep thoughts, leap from one conversation to another, tell details of a funny story, and rely on the loved one for advice. There are many other things that may be missed, such as the following:

- The person with AD no longer can plan and cook a holiday meal because she can no longer follow recipes, remember favorite foods or plan accordingly.
- The person with AD no longer can pass along his hobby of assembling model airplanes to his grandchildren as he no longer has the motor skills to assemble the small parts.
- The person with dementia may be unable to tell treasured family stories.

One notable thing about AD and related dementias which could seem ironic is that as the disease progresses, it becomes much more difficult for the family caregiver than for the person with AD. Many people with AD appear to live in the moment with no concerns about problems relating to everyday life. Years into the disease a person may lose self-awareness, become unaware of their decline, and grieve little, if at all.

A sad expression on the face of a person with AD may mean that the person is dwelling on long term memories such as missing a childhood friend, those activities, or close family relationships, especially their parents. Often a distracting activity such as pleasant music, bright flowers or even a familiar, wonderful smell like bread or cookies baking may change sadness to delight. If a person with AD becomes depressed, medicine may help with symptoms.

During the final years of AD, a person may have lost his or her sense of self and may seem easily comforted by a gentle touch, warm smile, or a small treat. During this stage the grieving of family members may be very intense as they try to manage the daily personal care of their loved one at home. Even with the assistance of a nursing home, the family caregiver may be deep in grief and need the

support and encouragement of staff at a facility and a support group.

### *Dealing With Loss*

Dealing with loss takes time. Each person needs to grieve in their own way and take the time needed to work through the emotions of sadness and hurt. Sometimes people progress straight through the three stages of grief; sometimes they go back and forth or skip stages. The loss of a long-term relationship runs deep; a loss that occurs slowly over many years runs deeper still.

## **Three Stages of Grief**

Though going through grief and loss have often been described as covering five stages of change and healing, this section discusses grief in terms of three stages. It is normal to dip in and out, back and forth, of the three stages; sometimes a person takes two steps forward and one step backward as they move through the process of grief. Many people struggle with anticipatory grief and some people need help for pathological grief, both of which are discussed after the description of the three stages of grief and suggestions for help.

**Stage 1: The Shock Stage:** During the first stage of shock, the person does not believe the news, experiences emotional stress or the opposite, numbness. They may misunderstand what they hear or see. They may not remember details or may remember them incorrectly.

**Suggestions for The Shock Stage:** Persons (either the person with the diagnosis or the caregiver) who are in the Shock Stage should talk to someone who is compassionate and a good listener about the news, the feelings, and questions about the news. Being with people who can provide love, support, and comfort at this time may include a trained listener such as a social worker, psychologist, nurse, mental health counselor, or clergy to help work out feelings. A trained health professional may help to answer additional questions about the diagnosis. Attending a support group may help to adjust to the news and to the slow changes over time.

It helps to keep notes about tasks/appointments to do, tasks that were done, who phoned or visited, etc.

This is the time to stay on a routine, not to make major changes.

**Stage 2: The Adjusting Stage:** The beginning steps to accept and adapt to the change or mounting loss occur, as the person enters the Adjusting Stage.

**Suggestions for The Adjusting Stage:** Persons who are struggling to adjust to the news and adapt to the current and unfolding changes may benefit by thinking in positive terms, such as the strengths, the pleasant interactions, and special, enjoyable characteristics of the person with dementia. Simplifying household tasks, doing satisfying activities, and laughing together at amusing incidents can help with the adaptation to the changes.

Exercise can help to deal with the frustration or sadness as well as provide a healthy activity for the body (and brain cells). Walking the dog or on a treadmill, yard work, household chores, washing and waxing the car, pet care, etc., can vent negative feelings, stimulate blood flow, and release good healthy chemicals through the body, such as neurotropic factors and endorphins. Exercise can help one relax such as yoga, listening to soft music, or sitting on the back porch watching a breeze rustle the leaves on trees.

Special restful activities may include time by the ocean or a lake, a visit to a museum or art shop, a picnic at a park or garden, or time at a worship or meditation center.

Writing down feelings or painting to express feelings may help.

**Stage 3: The “New Life” Stage:** As the person adjusts to a different schedule, a different way of managing, different interactions and relationships, and begins to look forward to new activities, the third stage, the “New Life” begins. The process of adjusting leaves behind the turmoil, anger, and sadness and moves toward accepting a new way of living. With time has come some healing. There is an emotional distance and “sweet sadness” to the memories of before (before the grief). Now it is time to move on to the next challenge of life.

**Suggestions for The “New Life” Stage:** Persons who enter the “New Life” stage begin to plan for the future. Doing activities with others such as a movie or a neighborhood party, taking respite for oneself, trying new interests, planning to do an activity that has been on a Wish List (If I had the Time and Money, I would ...). This is not the time to make major life changes such as selling your home or buying a new car. Small changes, however, may help such as getting a pet, volunteering for a fun

activity, touring some garage sales and spending up to \$2, or attending a sports event (there are lots of free children's sports events to attend).

### *Anticipatory Grieving*

Grieving that occurs before the loss happens is called "anticipatory grieving." Knowing or fearing that loss will come, people often predict the difficulties of the future and immediately feel the weight of their future burdens. With AD and related dementias, family members will grieve at the time of diagnosis as they anticipate the loss to come. Family members often feel the sadness of the death earlier than expected; they may have crying spells, become depressed, lose their appetite, and have trouble sleeping.

Sometimes the grieving, healing and recovery of the caregiver are completed before the relative actually dies. As a result, the grieving at the time of death may be very mild. It may seem as if a family member does not mourn the death; however, what has happened is that the grieving and recovery have been completed. The family caregiver has dealt with the situation, worked through personal feelings, and adjusted to the change.

Suggestions to Help Anticipatory Grieving: Health care providers can help family members deal with loss but the provider must also be able to address the loss they may feel as well. Regular support, encouragement, and planned celebrations such as family caregiver birthdays and annual holidays can help them remember and celebrate the pleasure and satisfaction that is also a part of the healing process.

### *Pathological Grieving*

Sometimes individuals grieve so deeply that they can no longer manage their own daily routine. As the months pass, they remain isolated and alone. They feel relief only with drugs or alcohol. When these circumstances occur or when people have multiple losses and feel like ending it all, they are in danger and need help at once.

Suggestions to Help Pathological Grieving: They should get professional help from a physician, trained clergy, a psychologist, counselor, social worker, and/or a supportive program in the community. A health care provider seeing family members in prolonged grief should try to refer them to expert helpers or programs.

## Summary

Family caregivers and health care providers should remember to focus on one moment at a time. In other words, caregivers should stay in the present and adapt the tasks and activities to the current abilities of the person with AD. It is essential for family members and health care providers to focus on what a person with AD and related dementias can still do and still enjoy.

Caregivers should:

- Keep a positive attitude and positive actions.
- Enjoy the moment.
- Use simple, brief steps.
- Take a deep breath to relax when stress builds up.

## Recommended Readings

ADEAR. (2009). *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging*. Bethesda, MD: National Institute on Aging. Alzheimer's Disease Education and Referral (ADEAR) Center. [www.adear@nia.nih.gov](mailto:www.adear@nia.nih.gov). or [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers). [www.nia.nih.gov/Alzheimers/Publications/CaringAD](http://www.nia.nih.gov/Alzheimers/Publications/CaringAD).

Alliance for Aging Research. (2008). *Alzheimer's Disease: Helping Yourself Help a Loved One*. Washington, DC: Alliance for Aging Research. Workshop kit from the Alliance for Aging Research, (one free copy; individual parts of kit downloaded for free) [www.agingresearch.org](http://www.agingresearch.org).

Alzheimer's Association. (2011). *Living with Alzheimer's; Caring for Alzheimer's; Coping; Grief and Loss*. (separate brochures free online) [www.alz.org](http://www.alz.org)

Kensington, MD. (2005). *1, 2, 3: Steps 4 Family Caregivers*. National Family Caregivers Association. (brochure, free online) [www.thefamilycaregiver.org/pdfs/123Steps.pdf](http://www.thefamilycaregiver.org/pdfs/123Steps.pdf).

McCurry, S.M. (2006). *When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver*. Westport, CT: Praeger Publishers/Greenwood Pub. Group, Inc.

# Chapter 15: Stress Management for Caregivers

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## Purpose

To educate healthcare providers (and caregivers) about the serious effects of chronic stress including caregiver burnout in caregivers of people with Alzheimer's disease and to improve coping skills in order to manage the long-term stress associated with caregiving.

Because caregivers typically have limited time to devote to stress management, quick (or short) techniques will show new ways of thinking and acting.

## Objectives

Upon completion of this session, individuals will:

- Understand the impact of stress that is built into (or comes naturally with) caregiving.
- Know about various coping styles and how to better apply them to caregiving issues.
- Know coping skills and techniques with simple actions to manage stress.

## Caregivers

Family members are the mainstay when it comes to providing long-term care to individuals suffering with Alzheimer's disease or related dementia (ADRD). Caregivers include spouses, children, other family members, and friends. By definition:

A caregiver is the following:

- A person who is responsible for the well-being of a person receiving care.

*Remember*, dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

- A person who provides a broad range of assistance, often without limits, for a person with a chronic and debilitating health condition.
- A person who is usually a close family member, partner, and/or friend with deep emotional ties.
- A person who is usually unpaid and lacking any formal training.

Caring for an individual suffering with ADRD is an exhausting and challenging task extending over several years, without expectation of improvement. Caregivers generally take on more and more responsibility as the disease progresses in their loved one and consequently neglect their own health and emotional well-being. This personal neglect can often jeopardize the quality of caregiving and can result in premature institutionalization of the loved one and increased medical costs.

Elderly caregivers, compared to people at the same stage of life who are not caregivers, are at increased risk for morbidity (illness) and mortality (death).<sup>1</sup> Sadly many caregivers become debilitated before the death of their demented loved one. Therefore, it is essential for caregivers to remain healthy by learning to cope successfully with the duties of caregiving.

The physical, emotional, and socioeconomic strains of caregiving are stressful, and if not properly managed or relieved, may lead to caregiver burnout. Burnout is a state of physical, emotional, and mental exhaustion accompanied by many negative feelings (e.g., guilt, anxiety, hopelessness, isolation, depression, resentment).

Burnout may lead to a dangerous shift from positive to negative caring with harmful behavior to the care re-

ceiver and/or premature placement in a care facility.<sup>1</sup> Helping caregivers to manage better the challenges of their roles has been shown to improve outcomes for all parties.<sup>1-5</sup>

### *What Is Burnout?*

- A state of physical, emotional and mental exhaustion accompanied by a host of negative feelings, often caused by excessive and prolonged distress.
- People who are approaching the point of burn-out often feel intensely overwhelmed and unable to meet the constant demands of caregiving.
- Burnout reduces a caregiver's productivity, physical strength, and emotional well-being. It can often lead to a dangerous shift in positive and negative caring, including increasing the risk of abuse.

## **What Are the Symptoms of Caregiver Burnout?**

Days in which caregivers feel bored, overloaded, or unappreciated are common. However if the caregiver feels this way most of the time, they may be experiencing burnout. Look for these telltale signs:

- Are they exhausted all of the time?
- Do they view every aspect of their day as negative?
- Are they voicing that “everything is a waste of time”?
- Is there evidence of:
  - Withdrawal from family, friends, and other loved ones?
  - No interest in hobbies or other activities previously enjoyed?
  - Feeling “blue,” sad, irritable, or hopeless?
  - Changes in sleep and appetite?

### *Definition of Stress*

There are several ways to define stress. In general, stress is the body's reaction to a change that requires a physical, mental, or emotional adjustment or response. Stress is related to external and internal factors. External factors

include interpersonal relationships, job pressures, financial struggles, and other challenges confronting us on a daily basis. Internal factors such as overall health, emotional state, and level of fatigue often determine how effectively we respond to or deal with the external factors.

Stress is a normal part of life, often motivating us to take action, to learn and to grow. As such, stress can be positive (called eustress), neutral, or negative (causing distress). Distress is the focus here because it is distress that negatively impacts caregivers and people in their care.

Long-term exposure to distress can lead to serious health problems and psychological illness. Chronic distress upsets nearly every system in the body and weakens immune system functioning, increases blood pressure and cholesterol production, and increases the risk of heart attack and stroke. Sleep disturbance, problems paying attention, headache, stomach upset, and hair loss are also common. Chronic distress can even rewire the brain, leaving a person more vulnerable to anxiety and depression.

It is important to first understand that there are critical differences in how individuals relate to perceived stress. These differences can have far-reaching consequences on our ability to effectively cope, particularly in times of distress.

### *What Is Coping?*

The definition of coping is the process of managing taxing circumstances, working hard to solve personal and interpersonal problems and seeking to master, minimize, reduce, or tolerate stress. Coping can also include behaviors that minimize stress as well as shift our insight, thoughts, and emotions.

A person's typical way of dealing with stress is referred to as their coping style. Most individuals rely solely on one type of coping style. For example, women in general tend to use an “emotion focused approach” while men often rely on a “problem solving approach.” However research has shown that some coping styles are healthier than others and that certain coping styles work best depending on the type of stressor a person uses.

When it comes to effective management of the long term stress of caring for a person with Alzheimer's disease, approaches that focus on the problem and the attached or underlying emotion can help one adapt and cope more successfully. Learning to manage stress better does not

## COPING STYLES & IMPACT ON STRESSORS

<b>AVOIDING:</b> Ignores the problem in hopes that things will improve or work themselves out	<b>GENERALLY INEFFECTIVE</b> method as it tends to increase stress over time
<b>PROBLEM FOCUSED:</b> Works hard to look for ways to improve or get rid of the problem	<b>EFFECTIVE METHOD</b> especially if problem is controllable and person has skills
<b>EMOTION FOCUSED:</b> Works to regulate or change emotional response to the problem which often involves seeking social support	<b>EFFECTIVE METHOD</b> particularly when problem is uncontrollable and unavoidable

erase all the challenges of caregiving. Also, it does not eliminate normal emotional responses such as sadness, grief, and guilt. Rather, it means during the process of caregiving, a person can take steps to be more resilient and thus, be able to recover more easily from stress.

### *Trying Different Ways of Coping*

It can be very useful to practice how to apply different coping styles to various types of stressors to help the caregiver understand the value in flexibility between styles. The following two examples describe problems and a suggested way of coping.

**Example #1: Stressor:** Worry over dangers if patient wanders away from home

**Coping approach:** Problem focused approach is aimed at securing doors and windows as well as activating an alarm chime or door noisemakers when exits open. Establish a neighborhood watch in advance and enroll a loved one in a Safe Return program. Find out from the County Sheriff and local law enforcement people the program or method they prefer to find a wanderer.

**Example #2: Stressor:** Feeling guilty over impatience with caregiving

**Coping approach:** Emotion focused approach includes realizing normal human behavior under stress, accepting one's limitations and shortcomings, and calling other caregivers for support.

### *The Serenity Prayer*

*“God, give us grace to accept with serenity the things that cannot be changed, courage to change the things that should be changed and the wisdom to distinguish one from the other.”*

*Karl Paul Reinhold Niebuhr, 1943*

The above Serenity Prayer also captures the important elements of effective coping and stress management.

Another major element in stress management is skill building!!

## **Skill Building**

Enhancing a caregiver's skills provides tools to help them cope with the numerous challenges that occur when dealing with their loved one. The following is a list of potential skills. More details on these specific topics are included in other chapters of this training manual.

**Building Knowledge:** education of the illness and what to expect with decline.

*Questions to consider:*

- What is the diagnosis?
- What symptoms can I expect?
- Who will answer our questions and help us?

**Ways to Learn:**

- Attend talks, read books and brochures, search the internet
- Learn about standard treatments, such as:
  - Medicines to help memory (cholinesterase inhibitors) and medicines to protect brain cells (anti-glutamnergics)

- Bionutritional: healthy diet, medical foods, food supplements, & vitamins
- Experimental treatments:  
Current Clinical Research Trials  
Check often: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
What is coming soon in the future?

### What are the possible behavior problems that may occur?

- Trailing (constantly following the caregiver), pottering (trying, but ineffective at doing tasks or personal care), wandering, aggression, resistance, incontinence, sleep disturbance
- When behavior problems occur, trying to understand the cause
- Possible causes for behavioral changes or problems include changes related to brain degeneration, over-stimulation, lack of stimulation, fatigue, acute or chronic illness such as an infection; sensory impairment such as loss of hearing, seeing, touch, taste, and smell; dehydration, effects of medicine, unfamiliar setting, task too complicated

### What resources are available in the caregiver's community?

- Federal and State agencies, Elder Care Options referrals, Alzheimer's Association, Alzheimer's Foundation, specialty providers (e.g., memory disorder clinics, neurologists, psychiatrists, psychologists, nurses, social workers, mental health counselors, geriatric care managers, etc.) crisis management options, respite care, adult day care, etc.
- Free online resources, such as:
  - [www.alz.org](http://www.alz.org)
  - [www.eldercare.org](http://www.eldercare.org)
  - [www.rush.edu/Rush\\_Document/Caregivers-Manual.pdf](http://www.rush.edu/Rush_Document/Caregivers-Manual.pdf)<sup>6</sup>

## Behavioral Approaches to Manage Stress

Perhaps the most challenging tasks for devoted caregivers are taking time for rest to refresh themselves and asking for help. Caregivers need to be sure to take care of their own bodies including proper nutrition, exercise, and rest. They must also take care of their minds and mental health. Simple behavioral techniques such as increasing pleasant activities or improving assertiveness can be useful. Other tips follow.

### *Tips for Caring for the Caregiver:*

- Take care of your health by eating balanced meals. Be sure to exercise daily even if done for just a short period. Do the best you can to sleep at least seven hours a night.
- Include pleasant activities in your daily life even when you do not feel like it. Listen to music, take a walk, sit quietly, work on a fun hobby. Do what you enjoy.
- Make time to pamper yourself on occasion. Get your hair done. Have a manicure or massage. Take a warm bath with music and candles.
- Read a light-hearted book or watch a comedy. Do what you can to add humor into every day. Laughter really is the best medicine!
- Try to set a time for outings. Seek out friends and family to help you so that you can have some time away from the home. If it is impossible to leave, have friends over to visit. Keeping social ties is important.
- Consider keeping a journal of your thoughts, feelings, and experiences. Writing it down can help to work through grief and to release negative emotions.
- Arrange a telephone contact with a family member, a friend, or a volunteer from a religious organization or senior center. Have someone call you each day to be sure everything is all right. This person can help by updating other family members and friends or let them know if you need anything.

Taking time for pleasant activities and/or keeping up with outside activities and relationships are necessary for the best mental health and successful long-term caregiving. However, caregivers often report feelings of guilt or abandonment if they allow themselves time away from their loved ones. No one person can continue round-the-clock care over years without respite and some assistance from others.

## Make Time for Yourself

Caregivers need to leave their loved one for a few hours or days on a regular basis. Small mental breaks or brief periods of separation help to reduce the toll of caring for a loved one. In fact, caregivers should be encouraged to take some time for themselves daily. Below is a list of potential activities that require only a small amount of time or that may involve the person receiving care.

### *Brief Time-Outs for Caregivers*

- Enjoy a cup of tea, cocoa, juice, some sparkling water, or soft drink
- Read something inspiring or your favorite magazine or section of the newspaper
- Pet a dog or cat; talk to your pet bird, turtle, etc.
- Walk around the yard and admire the scenery
- Go for a walk around a pond or lake
- Feed or watch outdoor birds or squirrels
- Sit under a tree and enjoy the breeze
- Listen to music or songs; play an instrument for a while
- Call a friend or family member and talk about something light hearted
- Meditate for 10 – 15 minutes
- Take a trip to a park or the zoo
- Go on a picnic or to the beach
- Keep handy a list of favorite hobbies and other activities
- Take a bubble bath or shower with music and candles

## *Caregiver Depression*

Caregivers often experience some symptoms of depression. Engaging in regular pleasant activities is a simple method of improving mood. Other effective methods include participating in a local support group, talk therapy with friends, mental health professionals, or spiritual counselors, and/or a trial of antidepressants.

### *Asking for Help*

Sometimes family and friends shy away from the ill person and caregiver as the illness progresses because they do not know how to help and they do not want to be an added burden. Sadly, caregivers often react with growing feelings of isolation and increased reluctance to ask for help, even though more help is needed. For caregivers, the act of asking for help may feel like one more chore to be done; they may hesitate to ask because of fear of rejection.

Encouraging caregivers to make and keep a wish list (see the following, *My Wish List*) on hand can be useful. It can easily be given to well-meaning family and friends who are willing to help but not sure how or what they can do. This simple technique provides caregivers a safe way to ask for things they need.

### *My Wish List*

*Please...*

- Call me if you go to the grocery store or on another errand. I might need something that you could pick up for me.
- Prepare a nutritious meal for us. I hardly have time to cook.
- Call me just to say “Hi” and see how I am doing.
- Don’t stop visiting me; I get lonely and enjoy your company.
- Come and tell me a joke or funny story. Laughter is good for me.
- Bring me my mail or pick up my newspaper.
- Take out my garbage or bring in the empty cans.
- If there is a storm coming, please help me prepare.
- Offer to watch my loved one, so I can go for a walk or take a short break.

- Come sit with my loved one, so I can go to a support group.
- Help me with yard work if my yard gets messy because I am so busy.
- Bring me flowers every once in a while – my loved one is no longer able to.
- Offer to vacuum or mop for me; chances are my back hurts.
- Take my loved one for a walk, so I can take a long shower or bath.

## Summary

Managing one's emotional and physical health over the years of caregiving for a loved one with ADRD can be overwhelming. As the disease progresses, caregivers are forced to take responsibility over every aspect of their loved one's life. Arming caregivers early and providing them with regular reminders during the disease process is extremely important. Equipping caregivers with skills that increase knowledge, minimize distress, and improve their coping can improve the quality of life for both the caregiver and the person receiving care.

## Resources

*Care for the Caregiver: Managing Stress.* (2005). Clarksburg, MD: American Health Assistance Foundation. (up to 10 copies free), [www.ahaf.org](http://www.ahaf.org).

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# Chapter 16: Driving & Progressive Dementia

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## Purpose

To describe briefly issues of driving safety especially as driver skills change in people who have declines in memory, thinking functions, and movement.

## Objectives

Upon completion of this session, individuals will do the following:

- Understand at least three changes in functions, such as a decline in memory, communication and/or ability to do skilled hand movements that may increase the risk of a driver accident.
- Learn the main points of a comprehensive driver evaluation.

*Remember,* dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home.

*Progressive dementia* refers to the ongoing decline of the dementia. Though Alzheimer's disease is the most common progressive dementia, many other types exist.

- Know at least three ways to increase safety when driving.
- Know about resources to explore alternatives in transportation.
- Overview Florida programs such as Silver Alert and SALT.

## Definition of "Driving" Used Here

Driving refers to driving any motor vehicle or any all-terrain vehicle, for example a car, a truck, a dune buggy, a van, an SUV, a trailer, a motorcycle, a golf cart, a lawn mower, a motor boat or motorized water bikes, a motorized scooter, a snowmobile, a rider-snow blower...in other words, any kind of moving vehicle with a motor.

## Three Sections of This Chapter:

**Section One: Safe Driving:** a focus on the importance of the driver who may be undergoing general health changes and ways for them to stay safe when operating a motor vehicle.

**Section Two: Safe Driving and Mild Cognitive Impairment:** a focus on the driving issues related to the person who is having some mild short-term memory problems and occasional, slight difficulties in other thinking functions, but appears to be functioning normally in their daily tasks on the job or at home.

**Section Three: Safe Driving and Alzheimer's Disease or a Related Memory Disorder:** a focus on the driving issues of people diagnosed with Alzheimer's disease or a related progressive memory disorder (dementia).

## Section One: Safe Driving

Important to being a safe driver are having good brain and body functions. People must be able to see well, to move arms and legs quickly and skillfully, and to have good memory, especially short-term memory. Also, critical are the following:

- Excellent concentration;
- Good judgment and the ability to make the right choices;
- The ability to adapt to change, especially sudden changes while driving; and
- The ability to complete complicated tasks.

People must be able to think about the current situation, constantly take in new information and quickly adjust driving behavior. As people experience changes in physical function, increased stress, multiple demands for their attention and time, and declines in health, their ability to be safe drivers may suffer. Though as a group, older drivers, experience fewer accidents, their rate of deaths increase due to their increased frailty, whether or not an accident is their fault.

### ***Demands on Driver Skills***

Driving is a demanding, highly complicated task. While driving on the road, small insects or rocks suddenly may hit the windshield or pieces from retread tires may slap the front or side of the car. The driver in front, who has been signaling a turn to the left, may suddenly turn right or stop. The car in the next lane may have a surprise flat tire, a “blowout,” which may quickly turn that car into the side doors of a nearby car.

To drive safely, one must be able to react quickly to such possible dangers. Safe driving requires focus, good judgment, and the ability to reason and make good, quick decisions. Safe drivers also must be able to see possible driving risks ahead of time and adjust the handling of their vehicle to avoid danger. Safe drivers must keep their car (and other motor vehicles they drive) in top working condition.

## **Safe Driving**

### **Under your control:**

- YOU, the driver, must be alert, healthy, skilled, careful and calm.
- Your car must be well maintained.

### **Not under your control:**

- The weather, the road, and other drivers!

### ***A Word About Medicine***

Medicines used daily or occasionally may affect driving. This concern also applies to over-the-counter medicine, minerals, vitamins, herbs, and other supplements a person takes. Starting a new medicine may cause temporary changes such as feeling light-headed or nauseous. After a few days on the new medicine, these problems may stop as the body adjusts to the new medicine.

When talking to your doctor about any medicine, together you and the doctor or nurse should review all the other medicines, minerals, vitamins, herbs, and other supplements you take. It helps also to check this list with your pharmacist!

### ***National Resources for Information About Medicines***

American Pharmacists Association  
[www.pharmacyandyou.org](http://www.pharmacyandyou.org)

National Association of Chain Drug Stores  
[www.nacds.org](http://www.nacds.org)

### **ASK YOUR DOCTOR AND PHARMACIST IF A MEDICINE(S) MAY AFFECT DRIVING.**

Watch for the following signs that may increase your risk as a driver. These signs need to be discussed with your doctor, who may need to change the medicine or the dose:

#### *Feeling:*

- a. sleepy or drowsy
- b. light-headed or dizzy
- c. nauseous

#### *Experiencing:*

- a. foggy or slow thinking
- b. slow body movement or weakness
- c. difficulty paying attention or focusing
- d. not scanning the road and other drivers
- e. not listening fully to what others are saying
- f. not remembering what others just said

### ***Issues That Increase Risks When Driving***

- Poor vision; unable to see ahead and predict problems on the road
- Poor hearing
- Limits on movement, such as weak muscles or inability to move quickly
- Poor memory, especially short-term memory
- Short or poor concentration
- Poor judgment

- Poor decision skills such as making wrong turns or not stopping at a red light or a stop sign
- Unable to do tasks with more than two steps
- Unable to deal with sudden change
- On medicine that makes you slow or sleepy

### *Refresher Courses*

A driver refresher or driver safety school course may improve and update driver skills. Special courses offered to older persons may suggest the following:

- Wider range rearview mirrors;
- Driving at low traffic times; and
- Avoiding busy intersections or high speed highways.

One such course is the AARP Driver Safety Program, an eight-hour refresher course for drivers age 50 or older. Some insurance companies offer reduced rates on a driver insurance policy with proof of attending a driver safety course. More information is available at 1-888-AARP-NOW (1-888-227-7669) or [www.aarp.org/drive](http://www.aarp.org/drive).

### *Safety Tips for Driving*

- At all times: be alert, listen, and watch other vehicles in front of, next to, and behind you. What are those drivers doing and how should you respond?
- Check eye health and glasses regularly. Keep all glass surfaces including eyeglasses, windows, and mirrors clean.
- Check hearing and hearing aids regularly.
- Always drive a little safer than others drive.
- Adjust side and rear-view mirrors for best, fullest views for you. Wide-range mirrors may help.
- Adjust seat and pedals (pedal extensions may help) so you clearly see cars and the road ahead of you.
- Exercise to keep your neck, arms, trunk, legs, and muscles strong, flexible and able to move well to operate the vehicle.
- Avoid distractions: no cell phones, especially no texting! No distracting food, liquids, arguments, make-up fixes, changing clothes, reading the paper, etc.

- Park the car to use a cell phone, iPod, etc., to make hard decisions, or to correct travel mistakes or problems.
- Drive the route you know; avoid short cuts.
- Go the easiest way. Take a right turn whenever possible; left turns are riskier.
- Predict problems: watch ahead and behind you for loose tire treads on trucks, oil slick, ice, rocks, debris falling from other vehicles, speeders, weaving cars or trucks, drivers who dart into small gaps between cars on the highway; flocks of birds, insects (“love bugs” in Florida).
- Avoid gawking at stopped cars or accidents on the highway.
- Don’t drink (at all) and drive!

## **Plan Ahead: You likely will outlive your ability to drive safely!**

As part of planning for future retirement, people should plan for mobility changes during the retirement years. As changes occur, transportation choices may need to adjust. The person who was the regular family driver may need to give up driver privileges because of health changes. Health changes such as reduced vision or arthritic pain may result in an obvious need to stop driving. Less obvious are declines in driving skills resulting from other health changes such as Alzheimer’s disease, stroke, or related disorders such as Lewy body disease which affects the ability to move.

There may be other family members, neighbors, volunteer drivers from community groups, buses or vans that transport people who are residents of a community or who participate in special programs. Some public transportation charges are lower for seniors at low-use times such as during the week, 10 a.m. to 2 p.m. Some of the programs limit the type of riders or the number of rides each week. Some rides are available on a fixed schedule from Monday through Friday only; others have a varied schedule which depends on the needs of the riders.

Some non-profit groups provide rides for sliding-scale fees, minimal fees, or donations. Transportation services such as taxis are expensive but people who no longer pay for car upkeep, new tires, repairs, insurance, tolls or gasoline may now be able to afford an occasional (or regular) taxi or van service.

Specific details on choices for rides in a community are located in county or city public transportation offices, senior centers, or offices of aging. See the following list of national and Florida contacts to begin to track down local services.

### *National Resources*

- ACTION (Accessible Community Transportation in Our Nation; an Easter Seals project) 800-659-6428 [www.projectaction.org](http://www.projectaction.org)
- Alzheimer's Association 800-272-3900 [www.alz.org](http://www.alz.org)
- ElderLocator 800-677-1116 [www.eldercare.gov](http://www.eldercare.gov)
- U.S. Department of Transportation, National Highway Traffic Safety Administration 888-327-4236 [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

### *Florida Resources: Florida Department of Elder Affairs (DOEA)*

- Florida Elder Helpline 800-963-5337
- Florida DOEA 850-414-2000
- Keeping Seniors Safe & Mobile (Dept. of Transportation): [www.safeandmobileseniors.org](http://www.safeandmobileseniors.org)
  - a. Florida Dementia Friendly Research Project
  - b. Silver Alert Program
  - c. Florida Senior Safety Resource Centers

## **Section Two: Safe Driving and Mild Cognitive Impairment**

Changes in the brain that affect memory, thinking skills, and actions eventually affect driving ability. Early brain cell changes may lead to a very small amount of decline in short-term memory and some minor difficulty handling complex events such as overseeing a business or organizing a class or family reunion.

Occasionally the person may experience some delay when trying to recall an exact name or word. Despite these mild difficulties, driving skills may remain strong. Driver skills are likely to be strong when there are no changes in driver ability, no recent accidents, no difficulties parking the

car, no problems handling surprise moves by other drivers, and no near misses, scrapes, or fender-benders.

However, some early brain cell changes may lead to a decline doing skilled hand movements. Problems doing skilled or coordinated hand movements may affect actual driving, for example, not being able to use the following:

- A tool to do a home repair such as fixing a door knob;
- A key to unlock a door; or
- A remote control.

A decline in hand skills often leads to less ability to manage driving a motor vehicle, whether it is a car, motor boat, or rider-lawnmower.

Driving may be less safe, not only for the passengers with the struggling driver but also for people in other cars on the road. Anyone with difficulty moving one or both hands or with general movements of the arms or legs should undergo a medical exam. If this difficulty is the beginning of a progressive disorder, a full medical check-up by an expert physician is essential. Also, a comprehensive driver evaluation may be important to make sure that the person can drive safely.

Look at the table "Are you a safe driver?" on the following page and answer the 19 questions.

### *The Driver With Mild Cognitive Impairment*

People who have only a slight short-term memory loss but still manage their daily tasks and interactions well may be diagnosed with a Mild Cognitive Impairment. Sometimes people with Mild Cognitive Impairment (called MCI), may also have occasional difficulty recalling the specific name of a street or the friend meeting them for lunch. Other occasional mild thinking difficulties may include keeping up with many topics that come up when a few passengers in the car are talking. Trouble may involve managing complicated directions to a place.

With a healthy lifestyle many people with MCI will not experience any further brain cell decline and will continue to be skilled, safe drivers. Others, despite their best and healthiest efforts, seem to convert over time to slow, deeper, progressive declines in memory and other thinking functions.

## ARE YOU A SAFE DRIVER?

Are you a safe driver? Yes or No. One Yes to any of the following questions should lead to a talk with your family and your doctor to see if a health change may mean you are at a higher risk as a driver.

1	Have you noticed any change in your driving skills in the past few months or within the past year?		
2	In the past six months, has anyone commented about your unsafe driving?		
3	Are you less sure of your overall driving skill?		
4	This past year did you, while driving, ever forget where you were going?		
5	In the past year, have you become lost while driving?		
6	Do other drivers honk at you or show signs of being angry at you?		
7	This past year, has anyone riding in the car with you suddenly said, “Watch out!” or “Be careful of that driver...” or “Don’t hit that...”?		
8	In the past year, has anyone refused to ride with you as the driver?		
9	In the past year, has anyone asked you to stop driving?		
10	In the past year, have you had any car accidents?		
11	In the past year, have you almost had a car accident (or close calls)?		
12	Are you having problems with parking: scraping curbs, bumping other cars, not able to fit in between the lines or into the space?		
13	In the past six months, have you had any slight scrapes or fender-benders with other cars in parking lots?		
14	In the past six months, while driving, have you scraped other objects in the garage or the bushes, fence, mailbox, or trees near your driveway?		
15	In the past year, have you received any traffic warnings or tickets for speeding, going too slow, turning improperly, not stopping, etc.?		
16	Have you missed seeing a traffic sign or red light?		
17	In the past year, have you confused the gas pedal and brake pedal?		
18	In the past year, have you been unsure about where to turn or exit?		
19	Do you need a “copilot” to drive?		

### *Short-term Memory and Driving*

Short-term memory and thinking functions are important for safe driving. For example:

- **If there is a slight decline in short-term memory:** A person must be able to remember information that was just heard or seen to be a safe driver. For example, remembering a sign or lit message board by the roadside about upcoming road repair or road hazards from weather changes are important in order to remember to drive more cautiously before approaching the hazardous area.
- **If there is a mild decline in naming:** A person must be able to read quickly and to understand

language such as names of places and signs with directions while driving along at the speed limit.

### *Early Full Medical Exam Is Important*

An early full medical evaluation when the symptoms, such as problems with memory first appear, will lead to receiving help. With a correct diagnosis, recommendations from the doctor may reverse the decline, stabilize, or improve function, or slow the rate of decline that is occurring. At the point of beginning decline, the person who is diagnosed with a Mild Cognitive Impairment probably still is fully safe as a driver of motor vehicles.

To determine if decline is ongoing in the person with Mild Cognitive Impairment, a medical check-up every

three to six months with the diagnosing physician offers a way to check on further changes. If medical findings suggest a decline in driver skills, then the physician may recommend limits on driving. In some cases the physician may recommend that the person should stop driving until passing a comprehensive driver evaluation.

Any reports from the person or the family (or significant other) of any risks in the above table (Are you a safe driver? Yes or No.) should lead to a comprehensive driver evaluation before the person continues to drive. Sometimes as a result of such testing, a driver refresher course or training with a driver safety specialist may update the driver's skills. A driver safety specialist may suggest adding features such as a wider rear-view mirror or larger side-view mirrors to the vehicle to increase the visual field of the driver.

### *Comprehensive (Full) Driver Evaluation*

A comprehensive (full) driver evaluation is more extensive than the regular driver test of the Department of Motor Vehicles and Highway Safety. The comprehensive driver evaluation test involves different vision tests, tests of memory and cognitive functions as well as an on-the-road test (some places use a virtual test, an indoor set-up designed to imitate on-the-road driving situations).

A driver safety specialist, who is certified in comprehensive driver evaluation, is trained in this type of evaluation and may offer some "driver rehab." Some of these specialists are occupational therapists; others have different training. Further information is available in the national and Florida resources listed at the end of this chapter.

### *Silver Alert: Helping to Find Lost People Who Have Dementia*

In 2008 Florida joined 26 states in the U.S. to develop a Silver Alert Plan. The Florida Silver Alert program helps law enforcement officers rescue people with Alzheimer's disease or a related dementia disorder who become lost. There are two parts to the Florida program:

- The State Silver Alert program uses a statewide "alert system" to recover people with dementia who are missing after driving in a motor vehicle.
- The Local Silver Alert program uses a local "alert system" to recover people with dementia who are missing as a result of walking, in other words missing "on foot."

The decline of Alzheimer's disease and related dementias damages the brain, which may lead to some people wandering and getting lost, even close to their homes. They may decide to drive or to walk to some destination and become confused, disoriented, then lost, and unable to ask for help.

Sometimes they stop driving only after running out of gas. They may trip or become tired while walking, rest briefly, and then forget their way. They may be unable to take the steps necessary to get home. They may be afraid or unable to ask for directions. They may not remember their current address or phone number. Their errors in judgment may lead to unsafe driving behaviors on the road such as driving south in a northbound lane, driving into a building, or driving into water. When on foot, they may walk in the wrong direction or decide to hide behind a building or bush for protection.

A caregiver or significant other in Florida may phone 911 to report a person with Alzheimer's disease or related dementia when the person has left home (or a health care facility) and not returned at a reasonable or expected time. After looking for the missing person for a brief time, a phone call to 911 can report the person as missing to law enforcement. Throughout the area, a message may be broadcast on the radio, local T.V. stations, through neighborhood telephone chains, in newspapers, and on highway message boards describing the missing person (with a photo where appropriate) and the color, make, and tag number of the vehicle.

Florida's State Silver Alert Program provides a coordinated response between local and statewide law enforcement agencies and the Florida Department of Transportation because the person may drive far from home. Florida's Local Silver Alert Program provides a coordinated response among local law enforcement agencies and the Florida Department of Transportation to search carefully in the local area in order to find the missing person as soon as possible.

The caller of a missing cognitively impaired driver should report:

- The person is missing and that there is a reasonable suspicion that the person is lost.
- The person has a diagnosis of a cognitive problem associated with a progressive dementia such as Alzheimer's disease or related disorders.

- The description of the person with a recent photo, if possible.
- The person takes medicine for Alzheimer's disease or related disorders.
- If in a motor vehicle, the make, model, year, and color of the car. The tag number and state.
- The last area where the person was seen.

Often people who are lost while “on foot” are within one mile of home but are still difficult to locate. They may be hiding and afraid to answer when they hear someone call their name. With this concern in mind, the Department of Elder Affairs suggests ways to find people who have become lost while “on foot,” such as the following:

- Search as soon as possible and as carefully as possible the immediate area where the missing person was last seen,
- Check open and closed places as well as open and closed doors, cabinets, boxes, etc.
- Call the person by a name that is familiar to them and in a calm, positive voice,
- Slowly increase the search area, and
- Then involve local law enforcement, for example phoning 911 to report the missing person.

Law enforcement will evaluate the information and link to various resources in the area such as the sheriff's office, the media, roadway message signs, local Alzheimer's Association offices, local Aging Resource Centers, the Elder Helpline, and the Department of Elder Affairs' email listserve, etc.

For more details about the Florida Silver Alert program, go to: <http://www.fdle.state.fl.us> or [www.floridasilveralert.com](http://www.floridasilveralert.com).

People who want to receive Silver Alerts broadcasts should contact: <http://lists.elderaffairs.org/listmanager/list-info/silveralert>.

Also, on the website are several types of equipment, for example, GPS (Global Positioning System which uses a satellite system to locate people or places), cell phone triangulation, radio frequency identification, and other items which are commercially available to keep track of people.

### *SALT (Seniors and Law Enforcement Together)*

Many Florida counties have a SALT program that involves seniors and law enforcement working together to do the following:

- Prevent crimes against the elderly;
- Increase sensitivity of officers when dealing with seniors;
- Recruit and train volunteers to assist law enforcement agencies; and
- Work on strategies and programs to reduce fear and provide moral support to seniors.

SALT programs educate older drivers and older pedestrians about safety. SALT programs partner with AARP (American Association of Retired Persons), the International Association of Chiefs of Police, National Sheriffs' Association, the National Association of Area Agencies on Aging, and other organizations to offer refresher driving courses that review the following:

- Aging changes related to vision, hearing, movement, and reaction time;
- Strategies to deal with health and aging changes;
- Driving rules; and
- Defensive driving tips.

To find SALT programs and to identify events in Florida, contact the following website: [www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm](http://www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm). Other helpful resources and information are available at the end of this chapter.

## **Section Three: Safe Driving and Alzheimer's Disease or a Related Memory Disorder**

Alzheimer's disease is the most common progressive dementia. This disease affects more than 5.4 million people in the United States and more than 524,000 in Florida. Many researchers think that cardiovascular dementia is the second most commonly occurring type of dementia while other researchers think that Lewy body dementia (also called Lewy body disease) is the second most common

progressive dementia. In addition there are a number of other types of progressive dementias.

Because Alzheimer's disease is the most commonly occurring dementia, this section of the chapter on Dementia and Driving focuses on Alzheimer's disease. Many of the points about thinking and movement declines discussed in this section apply to specific declines that show up in the other kinds of progressive dementias.

### *Overview of Alzheimer Disease and Thinking Changes*

People with Alzheimer disease and related disorders have decreases in brain cell function that affect their abilities to think and process information. The changes in brain cells of people with Alzheimer's disease typically affect short-term memory first and then other thinking functions such as the following:

- Difficulty recalling specific names of people, objects, or places;
- Not being orientated to the current time and place;
- Unable to do complicated tasks such as planning the details of a future event, evaluate choices, make good decisions, track family finances (paying bills, tracking the savings accounts and balancing the checkbook); and
- Trouble keeping up with normal duties, schedules, and relationships at work or at home.

## **Impact of Decline on Driver Safety**

As Alzheimer disease progresses the decreases in brain cell functions are likely to increase driving risks. The different areas of decline impact driving skills in different ways, such as the following:

1. **Decline in short-term memory:** A person must be able to remember information that was just heard or seen to be a safe driver, for example, remembering a sign by the roadside in order to do the following:
  - a. Make an appropriate turn or to exit the highway;
  - b. Prepare to pay a toll;

- c. Slow down for an upcoming school zone;
- d. Stop for a pedestrian to cross the street;
- e. Watch out for road repair or detours; and
- f. Watch out for hazardous driving due to weather changes.

2. **Decline in naming:** A person must be able quickly to read and understand language such as names of places, directions such as "right turn only" or "left lane ends 100 feet ahead," and warnings such as "detour ahead" or "flash flood during rain."

3. **Decline in learned skilled hand movements:** A person must be able to use both hands and arms smoothly and quickly in coordinated ways to drive safely. People with difficulty using one or both hands or arms need to undergo a full medical evaluation by a physician specialist to determine if the difficulty may be an early sign of a progressive dementia. If the person has a progressive decline in skilled hand movements (the medical term is apraxia), then a physician's exam may result in removal of driver privileges.

A person with progressive apraxia, who should not be operating motor vehicles, also should not be handling dangerous tools such as power cutting tools, food choppers, leaf or snow blowers, and sharp tools such as electric knives, razors, box cutters, and scissors.

4. **Decline in vision and perception:** A person must be able to see, understand and respond correctly to details on the dashboard and instrument panel of the motor vehicle as well as street signs, other vehicles on the road, and objects or people on the sides of (or in) the road. For example, the safe driver must see the following:

- a. Road signs and signal lights clearly;
- b. Signs on other vehicles, special signs on buses such as "stops at railroad crossings," or signs on trucks such as "extra wide load";
- c. Cars approaching (a driver should not be caught off guard by a car suddenly appearing from nowhere and moving close behind, next

to, or in front); and

- d. A person behind a parked car darting out to the street.
5. **Slowed thinking:** A person must be able to take in information, process it, and act on it quickly to be a safe driver. Driving involves a great deal of seeing, hearing, thinking, and moving to operate a vehicle safely. Slow processing of information (slow thinking) may lead to accidents because there was not enough time to do the following:
- a. Read through the whole sign;
  - b. Think through all the details of the setting;
  - c. Respond ahead of time, such as to an approaching emergency vehicle; and
  - d. Act quickly and safely.

Some researchers describe the smaller amount of information that is seen (visually taken in and acted upon) as a smaller useful field of vision. The useful field of vision describes what we see, how much we see, and how fast we work on the information in our brain and move our body to react or carry out a task. The driver may be working hard and fully intend to be as safe as possible, but slower thinking results in fewer details being considered and used in order to adjust driving actions. Thus, the driver may be focusing on the road and the lights at the intersection up ahead and miss seeing the door of the parked car (in the right lane) begin to open. Missing that information may result in hitting the door and person who began to step out of the car.

In summary, slowed thinking and decreased useful field of vision may lead to missing sight of the following:

- Objects in the road ahead;
- Drivers in the side lane or lanes behind you;
- Slow pedestrians trying to cross the street;
- Children on bikes who may skid on a rock or sand;
- Children playing with balls or toys with wheels; and
- An object flying through the air toward your vehicle.

6. **Decline in decision-making:** A person must be able to consider ongoing, changing details and make quick, safe appropriate choices while driving. For example, the safe driver must avoid changing to the next lanes when in the distance there is a car speeding forward in that lane.
7. **Decline in judgment:** A person should think about choices, possible consequences of each choice, and past experience with such choices. Also important to consider are the value, usefulness and appropriateness of the final choice. For example, the safe driver should do the following:
  - a. Schedule an appointment during the time of day with little traffic;
  - b. Keep headlights on for safety and definitely for more than 30 minutes after sunrise and before sunset and always on during cloudy weather;
  - c. Fill the gas tank when it is about one-fourth full, not when near or on “E” (empty);
  - d. Choose a parking spot that is easy to get into and out; and
  - e. Never try to “teach that other driver a lesson.”
8. **Decline in sense of direction (visual-spatial skills):** A person must know the correct direction and how to follow easy directions to find a location. For example, a person must be able to do the following:
  - a. Drive in the north bound lane when going north, etc.;
  - b. Signal a right turn before turning right; signal a left turn before turning left;
  - c. Turn into the appropriate lane enough ahead of time to avoid a sharp, sudden turn at the intersection or exit ramp; and
  - d. Merge with other traffic correctly...noting the speed of other cars to allow enough time and space on the road before merging into that lane.

9. **Slowed movement:** A person must be able to turn her or his neck easily from side to side to scan all the mirrors (side mirrors and rear view mirrors) as well as to move arms and legs quickly to adjust driving actions to changes, especially to sudden changes by other drivers. A safe driver must be able to do the following:
- a. Allow enough space between vehicles to allow for changes or quick stops to avoid any accidents;
  - b. Move quickly to allow an approaching emergency vehicle to pass; and
  - c. Move into a “safe space” at any time, for example move into the next lane or the break down lane quickly to avoid a sudden crisis such as a fender bender or hitting road debris, an animal, or person dashing across the road.

### *Limiting or Removing Driving Privileges*

Many people who are aware of changes in their ability to deal with the demands of driving will take the initiative to stop driving. Some people will limit driving to low traffic places or times. Others will drive only when there is a “copilot” (someone seated in the front passenger seat to notice upcoming activity on the road or to give frequent directions). Some people will stop driving based on the request of a family member or other loved one.

### *Tips to Help Someone Stop Driving*

- Give a consistent message: No driving.
- Plan ahead early with other choices for rides.
- Telephone-order deliveries of food, medicines, etc., to the home.
- List specific reasons why a person should stop driving: problems with vision, medical prescription or letter from physician to stop driving; accidents; near misses (give dates and describe details).
- Ask person’s help to keep family, such as your grand kids, safe.
- Ask person’s help to keep others on the road safe.
- List and schedule other activities (instead of going for a ride): walks, yard work, bird watching, ride from friends or taxi to a meeting, etc.

### *The Challenges of Stopping Driver Privileges*

In order to ease the level of family stress or to prevent a strong negative reaction when a loved one appears to be an unsafe driver but insists on driving, the family should ask the physician to address the question of driving privileges. When the family physician identifies clear health changes that increase driving risks, discussing how such health changes increase driving risks may convince the unsafe driver to stop driving. In some cases, the physician may be unsure about changes in driving ability and may refer the person for a comprehensive driver evaluation.

Not only is it hard for some family members, but also for some physicians to address the removal of driver privileges. Some older drivers have never had an accident, have never been cited for a driving violation, and have used their driving skills to save the lives of others. Some people with military backgrounds have driven all kinds of vehicles in many dangerous situations with no history of mishaps. Some elderly drivers, through their ability to drive, maintain the self-sufficiency of their own family unit, many neighbors, and others who are unable to drive.

Some elders learned to drive before they were teenagers in order to help on the family farm or ranch. Driving has become so much a part of their identity, function, independence, and sense of purpose that it is hard for them to remember a time when they did not drive or to consider a time when they can no longer drive.

The independence, pride, and mobility that driving provides for people make it difficult for some to leave behind that role. In a way it is a deep loss. Memories and emotions surface with the issue of “not driving.” The emotions may be difficult for the family and the physician to process. There may be a stronger grief reaction than when they learned about the diagnosis of Alzheimer’s disease. Or, the removal of driving privileges may be “the final straw” and hit them with the loss and changes of AD.

Sometimes appeals to reason or failing a comprehensive driving evaluation are not effective in convincing a person with dementia to stop driving. Occasionally the family caregiver will continue to allow the person with dementia to drive despite the physician’s insistence to stop. The family member may disagree with the conclusions of the physician or may struggle because it is too stressful to deal with their loved one’s sadness, sense of humiliation, anger or refusal to cooperate. In some settings, especially in

rural areas, it may be difficult for the family to meet their basic daily needs without a family driver.

### *The Help of a Physician*

When there are signs of a memory disorder, a medical evaluation by an experienced dementia specialist is critical. The medical evaluation may uncover a fixable problem such as a vitamin B deficit, a hormone imbalance such as low thyroid, or a medicine for urine incontinence that interferes with memory function. The medical evaluation may find a condition such as high blood pressure or irregular heartbeat that under treatment leads to improved memory, better cognition, and slowed decline.

Other people with progressive conditions such as Alzheimer's disease may show improved function with some "memory boosters and protectors" [anticholinesterase medicines such as Aricept® (donepezil®, a product of Eisai/Pfizer), Exelon® (rivastigmine®, a product of Novartis) or Razadyne®, (galantamine®, a product of Janssen) or neuroprotective medicines such as namenda® (memantine®, a product of Forest Pharmaceuticals).

The medical evaluation should include questions about driving. If the person is still driving, the physician should consider carefully how the health changes may impact driver skills. The physician should document the findings in the person's medical record.

Sometimes it is unclear if the person can still operate a motor vehicle safely. In those cases, the physician should recommend that the person undergo a comprehensive driver evaluation test before continuing to drive.

A diagnosis of Alzheimer's disease is not enough to remove driver privileges; level of skills and safety are the important issues. States in the U.S. vary in their reporting mandates to physicians regarding health changes and driving. As of 2010 nine states (plus Washington, D.C.) require reporting, for example in California the physician must report a diagnosis such as Alzheimer's disease to the state offices of the Department of Transportation, which then provides a medical review and considers possible removal of driver privileges.

The American Medical Association (2nd edition, 2010) lists each state and the requirements for physician reporting in its publication, "Physician's Guide to Assessing and Counseling Older Drivers." The guide was written in cooperation with the U.S. Department of Transportation,

National Highway Traffic Safety Administration. For further information, contact:

- American Medical Association at [www.ama.org](http://www.ama.org); phone 313-464-4179
- U.S. Department of Transportation, National Highway Traffic Safety Administration at [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov); phone 888-327-4236

Often by the time a person has undergone a medical evaluation for serious problems in memory, language ability, and other thinking functions to the point that the family is concerned about the possibility of Alzheimer disease, the person no longer can operate a motor vehicle safely, thus should not be permitted to drive. In these cases, the physician should be very clear about stressing "no driving" to the person and anyone else coming to the evaluation with that person.

**NOTE: The physician should document in the person's medical record: the findings, the discussion, and who, such as a family caregiver, was present during the discussion.**

### **Steps to Report an At-Risk Driver**

Anyone, whether a physician, relative, neighbor or other person, or agency, may report someone who appears to be an unsafe driver to the Florida Department of Highway Safety and Motor Vehicles. The identity of the person making the report stays confidential. In addition, Florida law states that no civil or criminal action may be brought against the person reporting the information.

The information about the unsafe driver should include the name, address, gender, date of birth, any medical conditions, if known, and comments about one or more examples of the unsafe driving behavior. A quick way to make such a report is to:

**Step 1:** Print out forms from: <http://www.flhsmv.gov/forms/72190.pdf> (HSMV Form 72190 - Revised 07/11, *Report a Driver Whose Ability is questionable (Denuncie a un Conductor Cuya Habilidad es Cuestionable)*)

**Step 2:** Fill out and fax the two-page form to 850-617-3944

**Step 3:** Make a note of the date, time, and person who faxed the form and file that form in a safe place. A report

by phone to 850-617-3814 may take more time but the call is still confidential.

## Summary

People with a Mild Cognitive Impairment or progressive dementia such as Alzheimer disease may have declines in brain cell function that affect their abilities to remember, to think clearly, and to act appropriately. These declines early on may not impact driving ability. However, over time declines typically begin to increase driving risks to themselves and drivers in the community. Sometimes a comprehensive driver test is needed to determine if the person can still drive safely. When a medical evaluation determines that the person is likely to be an at-risk driver, the physician should request that the person stop driving.

Below are tips for stopping an unsafe driver, list national and Florida resources, and other sources that provide additional information.

### *Tips to Stop an Unsafe Driver*

- Have a family meeting and ask (or plead) that the person stop driving.
- Have a special picture I.D. made to replace driver's license. Most Dept. of Motor Vehicles will provide this I.D. for a small fee.
- Keep a "Do Not Drive" note in large print or a Prescription from the physician on the refrigerator door, on the garage door, and in the car on the driver's side (steering wheel, driver's seat or visor).
- Hide the car keys. Keep car (one block away) in a neighbor's garage.
- File down the ignition key so it fits into the ignition but does not start the car. For a remote door opener (and key), remove the battery.
- Donate the car to a deserving family member or charity (a tax deduction!).
- Redo car upholstery to give the interior a very different look. It may be too hard for the person to adjust to the "new look" and to figure out how to drive in the "new car."
- Buy a different car. The different model, style, color, dash board, and smell should make it impossible for the person to learn how to drive.

- Disable the car: remove distributor cap, disconnect spark plugs.

## Listings of Important Resources

### *National Resources*

ACTION (Accessible Community Transportation in Our Nation; an Easter Seals project) 800-659-6428, [www.projectaction.org](http://www.projectaction.org)

Alzheimer's Association 800-272-3900, [www.alz.org](http://www.alz.org)

American Medical Association 313-464-4179, [www.ama.org](http://www.ama.org)

American Occupational Therapy Association (AOTA) [www.aota.org/olderdriver](http://www.aota.org/olderdriver)

ElderLocator 800-677-1116, [www.eldercare.gov](http://www.eldercare.gov)

U.S. Department of Transportation, National Highway Traffic Safety Administration 888-327-4236, [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

### *Florida Resources: Florida Department of Elder Affairs (DOEA)*

Florida DOEA 850-414-2000, [www.elderaffairs.org](http://www.elderaffairs.org)

Florida Elder Helpline 800-963-5337

Florida Silver Alert: [www.floridasilveralert.com](http://www.floridasilveralert.com)

Keeping Seniors Safe & Mobile (Dept. of Transportation): [www.safeandmobileseniors.org](http://www.safeandmobileseniors.org)

- a. Florida Dementia Friendly Research Project
- b. Silver Alert Program
- c. Florida Senior Safety Resource Centers

SALT (Seniors and Law Enforcement Together): Florida page [www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm](http://www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm)

### *Educational Websites*

Alternative transportation: <http://www.eldercare.gov>

Association of Driver Rehabilitation Specialists:  
<http://www.aded.net>

Car Fit:  
[www.carfit.org](http://www.carfit.org)

Driver refresher courses:  
<http://www.aarp.org/drive>;  
[www.aaapublicaffairs.com](http://www.aaapublicaffairs.com)

Drive Well: <http://www.asaging.org/drivewell>

Drivable (a Canadian program):  
<http://www.driveable.com>

Driving & Dementia Toolkit (published in Journal of the American Geriatric Society):  
<http://rgapottawa.com/dementia/english/default.asp>

Florida At-Risk Driver Council, Florida Senior Safety Resource Center. The Effects of Aging on Driving Ability. (February 2004).  
<http://www.hsmv.state.fl.us/dll/atriskdriver.pdf> or  
[www.fssrc.phhp.ufl.edu](http://www.fssrc.phhp.ufl.edu)

Grand Driver information & references:  
<http://www.granddriver.info/>

Independence Drive:  
<http://driving.phhp.ufl.edu/index.php> (NODRTC website);  
<http://www.phhp.ufl.edu/ot/> (OT website);  
<http://www.IndependenceDrive.phhp.ufl.edu>

Older driver facts:  
<http://www.seniordrivers.org>;  
[www.nhtsa.dot.gov](http://www.nhtsa.dot.gov); [www.aoa.gov](http://www.aoa.gov)

### ***Free Booklets***

At the Crossroads: A Guide to Alzheimer's Disease, Dementia & Driving. (2003). The Hartford. [www.thehart-](http://www.thehartford.com/alzheimers)

[ford.com/alzheimers](http://www.thehartford.com/alzheimers); Also: We need to talk...

Age Page. Age Page on Older Drivers. (Free Brochure). 1-800-222-2225 [www.nia.nih.gov/health/agepages/drivers.htm](http://www.nia.nih.gov/health/agepages/drivers.htm).

Driving When You are Taking Medications. (Free Brochure DOT HS 809 777) 8/04.

National Highway Traffic Safety, U.S. Dept. of Transportation. DOT Auto Safety Hotline: 1-888-327-4236. [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov).

Physician's Guide to Assessing and Counseling Older Drivers (booklet). (9/03) (AA34:02-520:15M7/03) (DOT HS 809 647) (ISBN: 1-57947-558-2).

American Medical Association at [www.ama.org](http://www.ama.org) or telephone (313) 464-4179.

U.S. Department of Transportation, National Highway Traffic Safety Administration at [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov) or telephone (888) 327-4236.

Safe Driving for Older Adults. (Free Brochure DOT HS 809 493) National Highway Traffic Safety, U.S. Dept. of Transportation. DOT Auto Safety Hotline: 1-888-327-4236. [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov).



# Chapter 17: Ethical Issues & Caregiving

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## **Purpose**

To teach about the ethical challenges of providing care while respecting the individual differences and preferences of people dealing with Alzheimer's disease or related memory disorders.

## **Objectives**

Upon completion of this session, individuals will be able to do the following:

- Understand the important points of ethics and virtue that relate to people dealing with Alzheimer's disease or related disorders.
- Identify the following important ethical issues for people dealing with Alzheimer's disease or related disorders:
  - a. Autonomy
  - b. Respect
  - c. Dignity
  - d. Making decisions
  - e. Informed consent and double informed consent
  - f. Preferences
- Learn ethical approaches to help people who are in the early, middle, or severe stage of Alzheimer's disease or a related disorder.

## **Basics of Ethics**

In simple words ethics guides us to do the right thing. Ethics provides rules, moral principles, a group standard, or a policy that helps people decide an ideal action. Thinking and discussing a good approach or good actions can help people make ethical decisions and avoid wrong or bad actions.<sup>1-5</sup>

### **Ethics provides rules, principles, or policy to guide ideal actions.**

Ethics asks the questions:

- “What is the best action I could do?” or
- “What is the best way to act toward this person in front of me?” or
- “What is the next step to help in the best possible way?”

Rules and established ways of acting direct a person to do what will help one person, a family, or the most people in a community. For example, an ethical approach to keep a person with Alzheimer's disease safe may lead to locking the outside gate that goes to the street rather than locking the person in a bedroom. An ethical way to keep a group of people safe may be to have the residents of an assisted living facility wear bracelets or anklets that trigger an alarm when they try to exit the facility rather than give them medicine to sedate them or physical restraints to keep them in a chair or bed.

## **Cultural Differences**

The ethics of cultural traditions set appropriate ways that people in a group or community are expected to act. Cultural traditions develop over many years, such as traditions for the following:

- Dressing a certain way;
- Acting in special ways to show respect to elders in the community; or
- Caring for an ill elder parent in one's own home, no matter how stressful.

Cultural differences may establish that important decisions and guidance should come from a matriarch, patriarch, trusted clergy, or other leader in the community.

## *Spiritual Values*

Sometimes when a person receives a diagnosis of Alzheimer's disease or related disorder, there is a sense of being out of control of one's life. Turning to spiritual beliefs or to a religious community may provide support. Symbolic routines and services may help the person with the diagnosis feel connected to others and to a Higher Being who will offer help, support, and comfort through the challenges of the disease. Spiritual and religious values may provide important guidance for the daily decisions of ongoing and end-of-life choices for care.

## *Fairness and Equity*

In the United States the values of equal treatment and access to services are strong national policies. However, people and organizations in the U.S. sometimes do not appear to practice these values. For example, some people who need medical care do not have fair and equal access to medical attention and treatment. Some people from under-represented racial or ethnic groups, rural versus city communities, or low socioeconomic settings; people with a developmental or acquired disability; people with little or no health insurance, etc., may not receive appropriate medical attention or care.<sup>4-7</sup>

Some people such as those with Alzheimer's disease and their family members may experience indifference or rudeness from health providers who state that "nothing more can be done." Sometimes the lack of such medical care relates to discrimination, in other words, poor or no health insurance reimbursement blocks access to needed services.

When there are limited resources, the discrimination may build. The ethical approach is to make sure that care resources are used as fairly as possible. People who have Alzheimer's disease or a related dementia may no longer have the memory and communication skills to be assertive about their health needs. Family caregivers who have grown up in disadvantaged circumstances may have never learned how to take the initiative with health providers. They may not be comfortable insisting on attention to their health needs and questions. A person outside the family unit with a passion for humane treatment and fairness as well as good interaction and assertiveness skills may be necessary to link such people to care resources.

## *Adapting to Changes*

Ethics may change as people or circumstances change (this material does not cover much about "situational ethics"). Sometimes strong rules are bent in special circumstances. For example, while wearing a suit and tie is expected for a special event, such as a family wedding, more comfortable, casual clothing such as a pullover and pants may be acceptable for someone with severe Alzheimer's disease who attends that event.

Other special circumstances may lead to ignoring some rules in order to provide emergency care. For example, during a natural disaster resulting from an earthquake or hurricane, teams of helpers may ignore the HIPAA Privacy Rule<sup>8</sup> in order to save lives, provide care, offer shelter, or help displaced family members find each other.

## *Summary about HIPAA<sup>8</sup>*

HIPAA: the Health Insurance Portability and Accountability Act of the U.S. Congress, 1996, established procedures to protect the privacy of health information of people. In summary, HIPAA demands that health, social and other service providers only reveal identifying information (such as name, address, social security number, and date of birth) about people who need or receive health and related services to providers who are directly involved in giving direct care or services and to people whom the care-receiver selects. People with a diagnosis of Alzheimer's disease or related disorders should identify early in the course of the disease at least one person to whom such private information may be revealed.

## *Individual Rights versus Public Safety<sup>9</sup>*

Challenges arise in the daily lives of family care providers and professional caregivers when caring for people with dementia. The challenges may demand a change from the usual way the family manages daily routines and care. The ethics of driver and community safety need careful consideration during this time.

For example, when the sole driver in the family and neighborhood develops Alzheimer's disease, eventually that person becomes a driver risk. The driver and the family caregiver may insist that the person with dementia has had a driver license for decades, never had any difficulties driving, and has the right to continue driving. They may insist that no bad accidents have occurred and that the driving is still safe.

On the other hand, adult children who visit occasionally may be extremely concerned about unsafe driving behaviors such as near misses on the road or car scrapes in parking lots. These early signs of unsafe driving that put the driver and others at risk may convince the adult children to set limits, such as urge the unsafe driver to stop driving or refuse to be passengers or allow their own children to be passengers in the car with that driver.

The person with dementia may insist on the right to drive and resist giving up driver privileges for various reasons such as having had only a couple of recent minor scrapes with mailboxes or bushes or the expense and inconvenient schedule of public transportation. It may take several actions such as a firm talk from the physician and failing a comprehensive driving evaluation to convince the person with dementia and the family caregiver to stop driving. Meeting with health and social service providers may help the family learn about alternative methods of transportation, such as rides from neighbors or community services.

### *Setting Limits*<sup>10</sup>

Another challenge in giving care is learning how to set limits. Setting limits is a subtle aspect of ethics that involves doing the right thing in terms of setting a limit to an action, a time, a place or setting. Setting limits recognizes the boundaries between people, respects individual differences and needs, and sets up what a person is willing to do and not willing to do. It sets up a time, place or other conditions for what is or is not acceptable (or appropriate). Sometimes changes in circumstances allow for setting up new limits such as when a person with dementia who cooked meals can no longer use the stove.

Setting limits involves balancing activities in ways that work toward the most pleasure and well-being of the family caregiver, not just the person receiving care. It may involve thinking about what is best for the most people in the family unit or the community.

An unethical consequence may result when the caregiver is unwilling to set limits on their efforts. Caregivers may work so hard to care for an ill relative that their daily homemaking, other responsibilities, and caregiving tasks lead to a lost sense of self and a disconnect from their own needs. The result may be caregiver exhaustion, illness, and collapse. It happens!

For example, in order to avoid exhaustion, caregivers may have to change their typical way of providing the “best” care. It may be more ethical to provide simpler levels of basic care. Taking short cuts may mean not doing some of the many extra tasks to keep the person with dementia dressed with all the typical accessories, worn previously. The house does not need to be perfectly immaculate and polished; clean works. Even though the caregiver is a great cook, to save caregiver energy, meals should be simpler with occasional potluck from family or neighbors who offer.

In a different example, adult children often consider bringing into their own home a parent who has severe Alzheimer’s disease and no longer can live alone. By thinking about setting limits, the adult children may realize that there is little room in their highly active family schedule with their current, overwhelming responsibilities, their employment demands, and their many commitments outside the home. They may realize that daytime caregiving tasks may be impossible; however, using help from an adult day health care program may make the plan work. Providing 24/7 care for a loved one with severe dementia may be unrealistic; however, residence of the parent in a special care unit or nursing home that is close by (within a 15 minute drive) may be the best ethical plan for the whole family unit.

## **Virtue**

Virtue is a sign of positive traits in a person, such as having the characteristic(s) of being honest, courageous, patient, good, beneficial, upright, etc. A person of virtue shows integrity and does what is right, not what is wrong. Traits of virtue can develop in a person from the influence of the family, school, religious teaching, and community settings. Virtue sometimes develops in a person through the person’s own self-discipline.<sup>1-4</sup>

### *The Virtuous Person is the Ethical Person*

Virtue reflects the identity or character of the person, not just actions of the person. Through practice, virtues become habits and thus typical, natural daily behaviors. Essentially, virtue refers to:

- doing the **right action**...  
for the **right reason**...  
the **right way**...  
at the **right time**, and  
with or for the **right person**.<sup>6</sup>

Some people feel that it is more important to act with virtue than to depend on rules to direct ones actions.

## The Impact of Decline Over Time

The next section contains a discussion of ethical principles such as changing autonomy, respect, dignity, making decisions, informed consent (and double informed consent), and preferences and how they vary in the different stages of Alzheimer's disease and related disorders.

### *Changing Autonomy*<sup>2, 3, 10-13</sup>

Autonomy means being in charge of one's self, making one's own choices and directing one's own life. The English philosopher, John Stuart Mill (1806-1873), described autonomy as being able to think, decide and act independently and freely over oneself. Having influence or control over others may occur when caring for young children or adults unable to care for themselves. Having such control must not harm others. While personal autonomy must be honored in those who have dementia, it is important to provide growing assistance and supervision to them as their decline shows evidence for such help.

While health professionals may have a strong influence over the treatment and ongoing care of people with Alzheimer's disease, in the early stage of the disease when memory and communication skills are still strong, the person with the disease should have autonomy to make informed decisions about daily routine choices and recommended health treatments.

Decades ago health care providers tended to be paternalistic. The paternalistic approach involves one person independently making decisions that affect someone else. For example, historically, the physician or other health provider made treatment decisions independently on behalf of the person with the disease. Because it was assumed that the "doctor knows best," often there was no input from the person undergoing treatment. The doctor made the choices.

Paternalism differs from the approach of beneficence. Beneficence involves doing good which involves minimizing the risks and maximizing the benefits so that care is done for the good of the person with the disease. The opposite of beneficence is maleficence, in other words, causing harm to someone. It is essential to avoid maleficence by outweighing the benefits of treatment against the risks and costs involved.<sup>10-13</sup>

A good ethical rule for care providers comes from the 4th century BC, the Hippocratic Oath of physicians that urges that health care providers not harm patients:

"...and I will do no harm or injustice to them..."<sup>14</sup>

While patient autonomy is more relevant to current medical decisions and practice in the United States, in the medical practices of the Middle-East and Asia, paternalism or an approach of beneficence in the health provider may be still more common.<sup>15,16</sup>

In the U.S. people with early dementia typically are able and prefer to be more actively involved in their own medical treatment decisions and ongoing medical care. Sometimes a medical paternalistic decision may be necessary to care for people in the early stage of Alzheimer's disease, for example when the current anxiety about being a future burden to loved ones or acting in embarrassing ways may result in threats of suicide.

Exercise of autonomy may occur easily through advance consent or refusal of medical treatment and/or care (advance directives such as durable power of attorney for health care/finances, living wills, etc.) that is documented. Such advance directives aid persons receiving care, their family members, and health providers.

In the middle stage of Alzheimer's disease (AD), the information about treatment and care should be simple, brief and concrete. However, it may be impossible to explain a treatment, such as repair of a fractured bone, to a person with a middle stage of disease because of the level of memory problems. Repeating a brief explanation in simple words should help the person with AD to understand the recommended treatment and to participate with partial autonomy in the care decisions.

When a person has severe dementia or is unaware of deficits in memory or thinking functions, explanations should occur in simple phrases or a single word. One detail at a time may be the best way to help them with treatment and care decisions. People at the severe stage of AD may be unable to understand the details of surgery and extensive care or remember for more than a few seconds. The physician and family caregiver may have to approach the treatment with paternalism and beneficence for the ultimate well-being of the person with AD. Though the repair may involve surgery and later pain during healing (despite pain medicine to help lower the pain), the

painful treatment and rehabilitation may be essential for quality of life.

Again it helps to have the person's preferences available ahead of the time they are needed. The person with dementia should have in written form the following information:

- The caregiver who has durable power of attorney for health (or is a health surrogate),
- The caregiver who has durable power of attorney for financial matters, and
- Advance directives.

### *Respect*<sup>2-5</sup>

Respect for other people involves looking up to them, thinking highly of them, being considerate and polite. Respectful behavior involves interacting with others in ways which show other people that their experience and/or opinions are valued. Aretha Franklin, a famous rhythm and blues singer, made "respect" a popular word when she spelled it out in the 1967 hit song.

"R - E - S - P - E - C - T"

A strong sense of self-respect and expectation of respect from others may exist in the early stage of Alzheimer's disease. As decline continues, however, the sense of self-respect and expectation of respect from others may grow weaker. Often people with the diagnosis of Alzheimer's disease or a related disorder will think ahead about how disabled they will become. Thinking about the future in this way may change their sense of self-respect to a growing disrespect for their body. They may become depressed, belittle themselves, or become angry especially when they struggle to function in ways that they used to do so well. They may turn the anger outward, act in negative ways such as yelling at or pushing the caregiver or family members.

Though the sense of self-respect may disappear, others should act with respect and consideration during interactions and especially when giving care. When speaking to people with Alzheimer's disease or a related disorder, a caregiver's voice should be clear with tones that show respect. The caregiver should use an appropriate, preferred name that the person will recognize and respond to. Choices for dress, activities, or food should reflect the

preferences of the person with the disease not the preferences of the caregiver.

### *Dignity*<sup>2-5</sup>

Dignity refers to a person feeling valued and worthwhile. Being treated with respect adds to a person's sense of dignity. Just as vulnerable groups of people have felt not valued and like victims who have no power, people with Alzheimer's disease may feel more vulnerable and less worthwhile as the decline continues.

In the early stages of Alzheimer's disease, when a person has small declines in memory, language and other thinking problems, the person probably still functions well enough to keep up with most of their typical daily work and home routines, which keeps the sense of self-worth and dignity strong.

In the middle stage the person with Alzheimer's disease needs more help to remember details, to communicate, and to do tasks. As they need more help from caregivers with the more complicated steps of personal care such as setting up the bathroom or helping with the actual bathing, the person with Alzheimer's disease may feel some loss of dignity. During this middle stage of Alzheimer's disease, the loss of dignity may be expressed in words or in feelings of anger or sadness that are held within or acted out. The caregiver should approach such behavior with patience, positive body language, words of encouragement and appreciation, and respect for feelings.

As the decline continues to the point of severe disability when the caregiver is providing most of the personal care, the person with the disorder may experience a great loss of dignity. Feelings of shame and embarrassment may grow. Without the ability to use words to communicate these feelings to others, the person with Alzheimer's disease may withdraw and refuse to participate in activities with others. They may do the opposite, act more restless or irritable, and hit others, yell out, or throw objects.

Setting up a simple routine, providing a reward for cooperation, and keeping a positive attitude, facial expression, tone of voice, and behavior are essential. They may refuse to allow any help with personal care though they cannot manage by themselves. Playing pleasant soft music beforehand may set a relaxed mood. A two-person approach may help, such as:

- The caregiver and care-receiver working together on the task, or
- Two caregivers providing care – with one talking to and distracting the person with dementia while the other person does the care tasks.

### *Making Decisions*<sup>12, 15, 16</sup>

Making decisions are important to controlling one's daily life even for someone with Alzheimer's disease or a related disorder. It is important to make sure that individuals with dementia respect the safe and reasonable choices of individuals who have dementia. The extent to which a person with Alzheimer's disease can make simple or complex decisions varies greatly and will depend on the person's personality and the amount of cognitive decline.

**Help to make decisions:** People with Alzheimer's disease or a related disorder should continue as much as possible to make decisions. Making personal decisions and participating in family decisions keeps people with dementia linked to others and strengthens dignity. In early stages of dementia, the person may need more time than is typical to make a decision. As decline continues, the person may need even more time to think and need fewer choices at a time. It may be easier for them to decide when there are only two items to consider. For example, while showing them two pairs of socks, ask:

*“Do you want to wear the brown socks or the white socks?”*

Later as the decline continues, one choice at a time may work, for example:

**Step 1:** Showing only the brown socks, ask the question:  
*“Do you want the brown socks?”*

Wait for an answer: *Yes or No*

**Step 2:** If the answer is “No”, then show only the white socks, and ask: *“Do you want the white socks?”*

Wait for an answer: *Yes or No*

The person with severe dementia may show a choice by smiling or focusing more on the white socks. Though taking extra simple steps to help the person with the disease to choose takes extra caregiver time, the effort may help the person with the disease to feel more in control. A sense of control may boost self-esteem.

### *Informed Consent (and Double Informed Consent)*

Informed consent refers to a person receiving an explanation of details about a task, action, or procedure, understanding the details, and then agreeing to the discussed task, action, or procedure. Double informed consent refers to the informed agreement of the person directly involved and the informed consent of a significant other, usually the primary caregiver or next-of-kin. Typically when a person has a memory problem or some other cognitive problem, a double informed consent is critical. Signatures of each person to provide written informed consent (essential documentation) should include the signature of a witness (a non-relative if possible).<sup>2, 3, 10, 17</sup>

When a medical procedure or research study is involved, the discussion of details may include the following:<sup>17</sup>

- Details of the procedure,
- Goal and expected results of the activity,
- Possible benefit or no benefit to the participant,
- Possible discomfort and available help,
- Possible risks, and
- Contact person (with phone number).

The person with early stage Alzheimer's disease should benefit from simple, careful explanations that start with a summary, cover details, and then repeat the summary. Then enough time for questions and answers should follow. It is important for a family caregiver (or significant other) to be present. Both the person with the condition and the caregiver should provide a written signature to show their Informed Consent for a procedure, treatment, or participation in research. Printed information should be available for them to take home.

For the person in middle stage Alzheimer's disease, a simpler explanation should involve a brief summary, one or two phrases about the procedure, and a repeat of the summary. It is very important that the family caregiver (or significant other) be part of the conversation. Then the health provider should ask for questions and allow time for answers and repeated questions. The family caregiver (or significant other) may help to translate an explanation in words that help the person with the disorder to understand. The health provider should repeat phrases, using simple words, and a positive facial expression. Both the person with the condition and the care-

giver should provide a written signature to show Informed Consent for a procedure, treatment, or participation in research. Printed information with illustrations should be available for them to take home.

For the person with severe Alzheimer's disease, a simple one or two word explanation should be repeated a couple of times. Explanations of details should be directed to the caregiver. It is important that the family caregiver (or significant other) be closely involved in the discussion, show understanding of the details, and has enough time for their questions. The family caregiver should provide reassurance, support and Informed Consent (the person with the disorder may be able to write an "x" as a signature). The family caregiver (or significant other) may help to translate the explanation in words that help the person with the disorder to understand. The health provider should repeat phrases, use simple words, and have a positive facial expression during the discussion. Printed material with illustrations should be available for people to take home.

### *Preferences*<sup>12, 17-19</sup>

The person with Alzheimer's disease should act on their preferences while they have good and safe decision skills. While communication skills are strong is the time to have the person with the disease identify their own preferences for daily routine activities such as dressing (comfortable clothes, colors of clothing, etc.), hair and grooming preferences such as using a beauty salon or shaving (or not shaving) facial hair, eating (meals, snacks, and non-alcoholic drinks), bathing (showers or tub baths), etc.

Attention should consider questions about special situations such as:

- Attendance at future events or ceremonies, such as weddings, anniversaries, funerals, etc.
- What arouses fear and anxiety in the person? For example, is the person afraid of dogs, cats, spiders, cockroaches, thunder, and lightning?
- What is the preferred way to avoid or handle such fears? For example, does the person prefer to manage such fears by: avoiding dogs (or other animals), avoiding clusters of bushes or trees, or listening to loud music indoors during stormy weather?

During the time when thinking and communication are stronger, preferences that apply to possible future illness or critical care should be discussed and written down. This information should be readily available for future use by the family, trusted friends, and the health providers for the time when the person with the disease may not be able to communicate well.

Legal documents may strengthen the wishes of the person with the disease, identify a trusted person(s) to make decisions on behalf of the person with the disease (durable power of attorney, durable power of attorney for health, or durable power of attorney regarding finances, etc.), and set-up preferences for difficult decisions such as living arrangements, financial decisions, and advance directives. Deciding about their future care may help the person keep a sense of dignity and control of their life over the long-term.<sup>17-19</sup>

**Deciding on behalf of:** If the preferences of the person with the disease are not available or unknown, a significant other or the family may be able to identify preferences. If no one has been designated to hold the durable power of attorney or durable power of attorney for health decisions, and if preferences are not known by the primary caregiver, other family members, or the significant other, then the next of kin may have to decide on behalf of the person with the disease.

If the time comes that a substitute decision-maker is called upon to decide on behalf of the person, the substitute decision-maker must follow as much as possible the expressed wishes or known preferences of the person with the dementia. If conflict develops, or, if the person's wishes are not known, are unclear, or are impossible to follow, the decision process should consider the following:

- The values of the person with Alzheimer's disease.
- The effect on the quality of life of the people who may be affected.
- The costs and benefits of a decision to the individual and other loved ones involved.

Any difficulty in reaching a decision should involve a neutral group such as an Ethics Committee, for example a Community Ethics Committee or Hospital Ethics Committee. An Ethics Committee can consider all the details objectively and propose recommendations.<sup>17, 20</sup>

## General Strategies for Ethical Caregiving

As decline in ability occurs, the caregiving work may vary from day to day. In other words, the person with the decline may need more help one day but then the following day may be able to do more and function better. The ethical approach makes sure that the people with Alzheimer's disease or a related disorder does as much as possible to stay active and involved.

### *Simple Steps*

When a task appears frustrating or too difficult, it is important to break the task into simpler steps. Each step of the task should be treated as a whole task. After each step, the person with the disease should receive words of praise and appreciation for the (one-step) task. Then the person can be asked to help with another task, in other words, doing the second step of that task. After that second step is finished, then words of thanks and appreciation should be given before moving on to the next step. Such steps help the person with dementia keep their dignity.

### *Tune Into Behavior*

When the person with the disease cannot communicate with words, the caregiver should look and listen carefully to facial expressions, body movements, grunts or other sounds being voiced to learn about the needs and comfort of the person receiving care. Emotion may be communicated in the look from a person's eyes, jaw tension, a smile, or grimace.

The family caregiver may be able to tell when the person with severe dementia still appears to enjoy a visitor, music, a snack or beverage, some time outdoors watching the fall leaves, or birds at a feeder. The caregiver as well as the person with the dementia may gain enjoyment and well-being from such moments. Though there may be great cognitive losses, such activities and interactions may still be positive and comforting to the person with dementia, and provide links of love with the caregiver, other family members, and friends.

The person with dementia should participate in conversations, routine decisions, and family activities. A person with Alzheimer's may lack some abilities such as being unable to cook or drive, but still may be able to choose preferences such as schedule of treatment or which step of a task to do first. Making such choices helps the person

with Alzheimer's disease or a related disorder keep a sense of autonomy, self-respect, and dignity.

## Summary

Ethics provides rules, principles, or policy to guide ideal actions and may reflect established cultural traditions. Ethics sets up appropriate, expected ways for people in a group or community to act. Virtue, on the other hand, is a positive characteristic within people, such as being honest, courageous, patient, good, upright, etc. A person of virtue shows integrity and does what is right, not what is wrong.

Families dealing with Alzheimer's disease or a related disorder meet many challenges regarding adapting ethical principles to the ongoing decline in abilities over the long term. The changes of dementia can impact autonomy, sense of self-respect and dignity, making decisions, informed consent (and double informed consent), and identifying preferences. The changing principles and actions involved in providing good care must also be sensitive to day-to-day fluctuations in the abilities of the person with Alzheimer's disease or other related disorders.

Though a person may have short-term memory problems, personal autonomy may be strong in that the person can still think, decide and act independently. Much later when decline impacts several thinking functions, regular help from a caregiver and thus a shared autonomy becomes necessary.

Self-respect, sense of self-worth and dignity may be strong in the early stage of Alzheimer's disease as the person manages to keep up with most of their typical daily job and home routines. As decline continues and the person with dementia needs more help to remember details, communicate, do job or household tasks, and keep up with personal care, their self-respect, sense of worth and dignity may decrease. The changes may lead to feeling depressed and frustrated with tasks that have become difficult and then either acting angry or sad and withdrawn.

Caregivers should provide the most freedom and the widest range of choices that are appropriate for the person with the dementia to help them maintain a sense of self-worth and dignity. As early as possible, the person with the disorder should identify in writing general preferences such as in diet, clothing, or leisure activities and set up (in writing with the appropriate signatures) advance

directives such as durable power of attorney, durable power of attorney for health, etc., and a living will. People with Alzheimer's disease may change their mind about preferences and advance directives, so occasional updating is important.

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# Chapter 18: Free Resources: Websites, Phones, Educational Information, & Materials

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Caregivers face a variety of challenges when a loved one develops Alzheimer's disease or a related disorder, including learning how to do the following:

- Manage family matters,
- Care for someone with a progressive disorder,
- Communicate with the person receiving care,
- Deal with behavior problems, and
- Handle caregiver stress and avoid caregiver burn-out.

The following are just a few of the free educational books, brochures, websites and programs that offer information and help for older persons and those dealing with Alzheimer's disease or a related disorder.

## National General Resources

### **Administration on Aging:**

Washington, DC 20201

1-202-619-0724

[www.aoa.gov](http://www.aoa.gov)

**ACTION:** Accessible Community Transportation in Our Nation; an Easter Seals project

1-800-659-6428

[www.projectaction.org](http://www.projectaction.org)

**Ageing Care:** Lists assisted living communities or facilities in the U.S.

[www.agingcare.com](http://www.agingcare.com)

**Alzheimer's Association:** General information, newsletters, free educational brochures, chapters and support groups in the U.S. and other countries.

225 North Michigan Avenue, 17th Floor

Chicago, IL 60601

1-800-272-3900

[www.alz.org](http://www.alz.org)

### **Alzheimer's Disease Education & Referral Center**

**(ADEAR):** Educational information, newsletters.

PO Box 8250, Silver Spring, MD 20907

1-800-438-4380

[www.alzheimers.org](http://www.alzheimers.org)

### **Alzheimer's Foundation of America (AFA):**

322 8th Avenue, 7th Floor, New York, NY 10001

1-866-AFA-8484 (1-866-232-8484)

[www.alzfdn.org](http://www.alzfdn.org)

[www.alzquilt.org](http://www.alzquilt.org) (a quilt to remember)

**Alzheimer Society of Canada:** Information, referrals, support services, advocacy, research funding (in English or French)

[www.alzheimer.ca](http://www.alzheimer.ca)

### **Alzheimer Outreach Services:**

[www.alzheimeroutreach.org/](http://www.alzheimeroutreach.org/)

### **Caregiver's Aide:**

[www.caregiversaide.com](http://www.caregiversaide.com)

### **Caring.com:**

[www.caring.com/articles/alzheimers-and-toileting-advice](http://www.caring.com/articles/alzheimers-and-toileting-advice)

**Eldercare Locator (Elder Care Locator):** Information and referrals about services and programs throughout the United States for older persons.  
1-800-677-1116  
[www.eldercare.gov](http://www.eldercare.gov) or [www.eldercarelink.com](http://www.eldercarelink.com)

**Executive Care, LLC of Florida:** Health services into the home (also services in New Jersey with Executive Care, LLC of New Jersey).  
1-954-767-4800  
[www.executivecarellc.com](http://www.executivecarellc.com)

**Family Caregiver Alliance:** Information, support, advocacy to caregivers.  
[www.caregiver.org](http://www.caregiver.org)

**Helping Caregivers:**  
email: [info@helpingcaregivers.com](mailto:info@helpingcaregivers.com)  
[www.helpingcaregivers.com](http://www.helpingcaregivers.com)

**National Adult Day Services Association (NADSA):**  
2519 Connecticut Avenue, NW,  
Washington, DC 20008  
1-800-558-5301  
[www.nadsa.org](http://www.nadsa.org)

**National Aphasia Association:** Education and support for people dealing with impaired use of (such as in speech, writing or reading) or understanding of words.  
350 Seventh Avenue, Suite 902  
New York, NY 10001  
1-800-922-4622  
[www.aphasia.org](http://www.aphasia.org)

**National Association of Area Agencies on Aging (N4A):**  
1730 Rhode Island Ave., NW, Suite 1200  
Washington, DC 20036  
1-202-872-0888  
[www.n4a.org](http://www.n4a.org)

**National Association of Professional Geriatric Care Managers (GCM):**  
1604 North Country Club Road  
Tucson, AZ 85716  
1-520-881-8008  
[www.caremanager.org](http://www.caremanager.org)

**National Family Caregivers Association (NFCA):**  
10400 Connecticut Ave, Suite #500|  
Kensington, MD 20895  
1-800-896-3650  
[www.nfcacares.org](http://www.nfcacares.org)

**National Hospice and Palliative Care Organization (NHPCO):**  
1700 Diagonal Road, Suite 625  
Alexandria, VA 22314  
1-703-837-1500  
[www.nhpc.org](http://www.nhpc.org)

**National Institute on Aging:** Part of the National Institutes of Health  
1-800-222-2225 or 301-496-6402  
[www.nia.nih.gov](http://www.nia.nih.gov)

## Websites About Research & Clinical Trials

**National Institutes of Health:**  
1-800-222-2225

[www.nia.nih.gov/health](http://www.nia.nih.gov/health)

Information about research and clinical trials:

- [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)
- [www.nia.nih.gov/Alzheimers/Publications/trials-studies.htm](http://www.nia.nih.gov/Alzheimers/Publications/trials-studies.htm)
- [www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials](http://www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials)
- [www.grc.nia.nih.gov/studies](http://www.grc.nia.nih.gov/studies)
- [www.nia.nih.gov/alzheimers/.../participating-alzheimers-disease-clini...](http://www.nia.nih.gov/alzheimers/.../participating-alzheimers-disease-clini...)
- [www.nlm.nih.gov/medlineplus/alzheimers-disease.html](http://www.nlm.nih.gov/medlineplus/alzheimers-disease.html)
- **Alzheimer's Disease Cooperative Study:** funded by the National Institute on Aging, a consortium of medical research centers and clinics working to develop and test drugs to treat Alzheimer's disease. [www.adcs.org](http://www.adcs.org)
- [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov) A comprehensive, searchable online registry of federally and privately funded clinical trials and studies.

**Alzheimer's Association:** Research information and research funding.  
1-800-272-3900  
[www.alz.org](http://www.alz.org)

**Center for Information and Study on Clinical Research Participation (CISCRP):** An independent, national nonprofit organization promoting greater understanding and awareness of clinical research participation and its role in public health.  
[www.ciscrp.org](http://www.ciscrp.org) or [www.smartparticipant.org](http://www.smartparticipant.org)

**Project IMPACT (Increase Minority Participation and Awareness of Clinical Trials):** An initiative of the National Medical Association, this site seeks to increase awareness and participation of African Americans and other minorities in clinical trials and research.  
[www.impact.nmanet.org](http://www.impact.nmanet.org)

**U.S. Food and Drug Administration (FDA):** FDA regulates all U.S. clinical trials of drugs and devices and offers information and resources for clinical trials participants and professionals.  
[www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ParticipatinginClinicalTrials](http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ParticipatinginClinicalTrials)

## National Resources about Driving & Safety Issues

**AAA Foundation for Traffic Safety Senior Driver:**  
[www.seniordrivers.org](http://www.seniordrivers.org)

**AARP Driver Safety:**  
[www.aarp.org/families/driver\\_safety](http://www.aarp.org/families/driver_safety)

**American Medical Association (AMA):** AMA information about at risk driving and each state's requirements for physician reporting: *Physician's Guide to Assessing and Counseling Older Drivers, 2nd edition* (2010). Written in cooperation with the U.S. Department of Transportation, National Highway Traffic Safety Administration. Free copy on AMA website.  
1-313-464-4179  
[www.ama.org](http://www.ama.org)

**American Occupational Therapy Association (AOTA):** List of comprehensive driving evaluation programs in U.S.  
[www.aota.org/olderdriver](http://www.aota.org/olderdriver)

**National Highway Traffic Safety Administration:**  
1-800-327-4236  
[www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

**U.S. Department of Transportation, National Highway Traffic Safety Administration:**  
1-888-327-4236  
[www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

## Educational Websites About Driving & Safety Issues

**Alternative Transportation:**  
[www.eldercare.gov](http://www.eldercare.gov)

**Association of Driver Rehabilitation Specialists:** Sites providing comprehensive driving tests.  
[www.aded.net](http://www.aded.net)

**CarFit:**  
[www.eldersafety.org/latest/roadmap-to-driving-wellness-and-car-fit-two-exciting-new-programs.html](http://www.eldersafety.org/latest/roadmap-to-driving-wellness-and-car-fit-two-exciting-new-programs.html)

**Driver Refresher Courses:**  
[www.aarp.org/drive](http://www.aarp.org/drive)  
[www.aaapublicaffairs.com](http://www.aaapublicaffairs.com)

**DriveWell:**  
[www.asaging.org/drivewell](http://www.asaging.org/drivewell)

**DriveAble:** A Canadian program.  
[www.driveable.com](http://www.driveable.com)

**Driving & Dementia Toolkit:** Published in *Journal of the American Geriatric Society*.  
[rgapottawa.com/dementia/english/default.asp](http://rgapottawa.com/dementia/english/default.asp)

**Florida At-Risk Driver Council, Florida Senior Safety Resource Center:** The Effects of Aging on Driving Ability. (February 2004).  
[www.hsmv.state.fl.us/dll/atriskdriver.pdf](http://www.hsmv.state.fl.us/dll/atriskdriver.pdf)  
[www.fssrc.phttp.ufl.edu](http://www.fssrc.phttp.ufl.edu)

**GrandDriver:** Information & references.  
[www.granddriver.info](http://www.granddriver.info)

## Independence Drive:

[driving.phhp.ufl.edu/index.php](http://driving.phhp.ufl.edu/index.php) NODRTC website  
[www.phhp.ufl.edu/ot](http://www.phhp.ufl.edu/ot) Occupational therapy website  
[www.IndependenceDrive.phhp.ufl.edu](http://www.IndependenceDrive.phhp.ufl.edu)

## Older Driver Facts:

[www.seniordrivers.org](http://www.seniordrivers.org)  
[www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)  
[www.aoa.gov](http://www.aoa.gov)

## Free Booklets About Driving Issues

*At the Crossroads: A Guide to Alzheimer's Disease, Dementia & Driving.* (2003). The Hartford. [www.thehartford.com/alzheimers](http://www.thehartford.com/alzheimers) Also: We need to talk...

**Age Page.** *Age Page on Older Drivers.* (Free Brochure). 1-800-222-2225 [www.nia.nih.gov/health/agepages/drivers.htm](http://www.nia.nih.gov/health/agepages/drivers.htm)

*Driving When You are Taking Medications.* Free Brochure DOT HS 809 777. 8/04 National Highway Traffic Safety, U.S. Dept. of Transportation. DOT Auto Safety Hotline: 1-888-327-4236 [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

**Florida Transportation.** *Lifetime Choices.* FL. Dept. of Highway Safety & Motor Vehicles & FL Dept. of Elder Affairs. 1-850-487-0867 [www.hsmv.state.fl.us](http://www.hsmv.state.fl.us)

*Physician's Guide to Assessing and Counseling Older Drivers* (booklet). (9/03) (AA34:02-520:15M7/03) (DOT HS 809 647) (ISBN: 1-57947-558-2)

- **American Medical Association:**  
1-313-464-4179 [www.ama.org](http://www.ama.org)
- **U.S. Department of Transportation,  
National Highway Traffic Safety  
Administration:**  
1-888-327-4236 [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

*Safe Driving for Older Adults.* (Free Brochure DOT HS 809 493) National Highway Traffic Safety, U.S. Dept. of Transportation. DOT Auto Safety: Hotline: 1-888-327-4236 [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov)

## General Reading

Many free publications at National Institute on Aging (part of the National Institutes of Health), Bldg 31, Room 5C27, 31 Center Drive, MSC 2292, Bethesda, MD 20892; see publications list at [www.nia.nih.gov](http://www.nia.nih.gov)

**ADEAR.** (2009). *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging.* Bethesda, MD: National Institute on Aging. Alzheimer's Disease Education and Referral (ADEAR) Center. [www.adear@nia.nih.gov](mailto:www.adear@nia.nih.gov) or [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers), [www.nia.nih.gov/Alzheimers/Publications/CaringAD](http://www.nia.nih.gov/Alzheimers/Publications/CaringAD)

**Alliance for Aging Research.** (2008). *Alzheimer's Disease: Helping Yourself Help a Loved One.* Washington, DC: Alliance for Aging Research. Workshop kit from the Alliance for Aging Research, (one free copy; individual parts of kit downloaded for free) [www.agingresearch.org](http://www.agingresearch.org)

**Alzheimer's Association.** (2011). *Living with Alzheimer's; Caring for Alzheimer's; Coping; Grief and Loss.* (separate brochures free online) [www.alz.org](http://www.alz.org)

**American Medical Association.** (2005). *Caregiver Self-Assessment Questionnaire.* Chicago, IL: American Medical Association, [www.ama-assn.org](http://www.ama-assn.org). (free printed packet online, assess emotional and physical well-being; English or Spanish)

*Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease (Guia para quienes cuidan personas con la enfermedad de Alzheimer).* (free online copy), Bethesda, MD: National Institute on Aging, December 2008. 24 pages from Alzheimer's Disease Education & Referral (ADEAR) Center. P.O. Box 8250, Silver Spring, MD 20907-8250. Pub.no: 01-4013. 1-800-438-4380; FAX: 1-301-495-3334. E-mail: [adear@nia.nih.gov](mailto:adear@nia.nih.gov). [www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm](http://www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm)

*Caregivers.* NY, NY: Home Box Office (HBO). 2009. From HBO Documentary Films. 1100 Avenue of the Americas, NY, NY 10036. 1-866-316-4814; 1-212-512-7467. NY, NY 10016. E-mail: [AlzheimersProject@cegnyc.com](mailto:AlzheimersProject@cegnyc.com), [www.hbo.com/alzheimers](http://www.hbo.com/alzheimers). Free Screening Kit at [www.hbo.com/alzheimers](http://www.hbo.com/alzheimers)

*Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging.* Bethesda, MD: NIA, June 2009. 136 pages. From ADEAR, PO Box 8250, Silver Spring, MD 20907-8250. 1-800-438-4380; 1-301-495-3311; FAX: 1-301-495-3334. E-mail: adear@nia.nih.gov. [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers) or [www.nia.nih.gov/Alzheimers/Publications/CaringAD](http://www.nia.nih.gov/Alzheimers/Publications/CaringAD)

*Communicating.* Alzheimer's Association, New York City, NY 2006. From Alzheimer's Association, New York City Chapter. 360 Lexington Avenue, 4th floor, NY, NY 10017. 1-646-744-2900; FAX: 1-212-490-6037. Email: helpline@alzny.org or [www.alzny.org/caregivers/communicate.asp](http://www.alzny.org/caregivers/communicate.asp)

*Communication: Best Ways to Interact with the Person with Dementia.* Chicago, IL: Alzheimer's Association. 2005. 12 pages. Living with Alzheimer's and many other booklets... from Alzheimer's Association. 225 North Michigan Ave., Floor 17, Chicago, IL 60601. 1-800-272-3900; FAX: 1-312-335-1110. Email: info@alz.org. [www.alz.org/living\\_with\\_alzheimers\\_communication.asp](http://www.alz.org/living_with_alzheimers_communication.asp)

*Communication Techniques.* NY NY: Alzheimer's Foundation of America. August 2005. 2 page brochure from Alzheimer's Foundation of America, 322 Eighth Avenue, 7th floor, NY, NY 10001. 1-866-232-8484. Email: info@alzfdn.org. [www.alzfdn.org](http://www.alzfdn.org). [www.alzfdn.org/EducationandCare/techniques.html](http://www.alzfdn.org/EducationandCare/techniques.html)

Kensington, MD. (2005). *1, 2, and 3: Steps 4 Family Caregivers.* National Family Caregivers Association. (brochure, free online) [www.thefamilycaregiver.org/pdfs/123Steps.pdf](http://www.thefamilycaregiver.org/pdfs/123Steps.pdf).

McCurry, S.M. (2006). *When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver.* Westport, CT: Praeger Publishers/Greenwood Pub. Group, Inc.

*Care for the Caregiver: Managing Stress.* (2005). Clarksburg, MD: American Health Assistance Foundation. (up to 10 copies free), [www.ahaf.org](http://www.ahaf.org).

## National Resources for Cardiovascular Dementia

**American Heart Association:**  
[www.americanheart.org](http://www.americanheart.org)

**American Stroke Association:**  
[www.strokeassociation.org](http://www.strokeassociation.org)  
[www.helpguide.org](http://www.helpguide.org)

**National Stroke Association:**  
[www.stroke.org](http://www.stroke.org)

## National Resources for Lewy Body Dementia

**Lewy Body Dementia Association:**  
1-800-LEWYSOS (1-800-539-9767)  
[www.lewybodydementia.org](http://www.lewybodydementia.org)

**Lewy Body Disease:**  
[www.helpguide.org/elder/lewy\\_body\\_disease.htm](http://www.helpguide.org/elder/lewy_body_disease.htm)

## National Resources about Sleep & Sleep Disorders

**American Academy of Sleep Medicine:** Sets standards for sleep disorders and identifies accredited sleep centers or labs.  
[www.aasmnet.org](http://www.aasmnet.org)

**American Sleep Association:** Improving public awareness about sleep disorders and sleep health.  
[www.sleepassociation.org](http://www.sleepassociation.org)

**American Sleep Disorders Association:** Information on sleep disorders.  
[www.asda.org](http://www.asda.org)

**National Sleep Foundation:** Information on sleep health and safety.  
[www.sleepfoundation.org](http://www.sleepfoundation.org)

**Sleep Research Society:** Information on all aspects of sleep.  
[www.sleepresearchsociety.org](http://www.sleepresearchsociety.org)

# Florida: General Resources for Older People

## Florida Department of Elder Affairs (DOEA):

1-850-414-2000

[www.elderaffairs.org](http://www.elderaffairs.org)

## Florida Elder Helpline:

1-800-963-5337

1-800-955-8771 TDD

1-800-955-8770 (Voice)

# Florida Driving Resources

**Florida Silver Alert:** Phone 911 to report someone diagnosed with Alzheimer's disease or a related disorder who has driven a motor vehicle and is missing,

[www.fdle.state.fl.us](http://www.fdle.state.fl.us)

[www.floridasilveralert.com](http://www.floridasilveralert.com)

**Keeping Seniors Safe & Mobile:** Department of Transportation

[www.safeandmobileseniors.org](http://www.safeandmobileseniors.org)

- a. Florida Dementia Friendly Research Project
- b. Silver Alert Program
- c. Florida Senior Safety Resource Centers

## SALT (Seniors and Law Enforcement Together):

To report an unsafe driver.

(850)617-3814

[www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm](http://www.nhtsa.gov/.../lawenforcementolderdriver03/florida.htm)

## Report a Driver Whose Ability is Questionable/

## Denuncie a un Conductor Cuya Habilidad es

**Cuestionable:** Medical Reporting Form: HSMV Form 72190 - Revised 07/11

- Download form at: [www.flhsmv.gov/forms/72190.pdf](http://www.flhsmv.gov/forms/72190.pdf)
- Fax form to State of Florida, Department of Highway Safety and Motor Vehicles, Division of Motorist Services at: (850) 617-3944

# Glossary: Understanding the Language of Care

By: Kathleen J. Houseweart, MBA, Coordinator, Sarasota Memorial Hospital Memory Disorder Clinic, 1515 South Osprey Ave., Suite A-1, Sarasota, FL 34239, Office 941-917-7197; Fax 941-917-4016. Partial support from Florida Department of Elder Affairs, Alzheimer's Disease Initiative. (2012)

This glossary provides basic descriptions of some of the services and agencies providing education, care, support, and referrals for people living in Florida. Services are in alphabetical order in the following sections:

- Map of Florida Showing 11 PSAs (Planning and Service Area)
- Finding Care
- 11 Planning and Service Areas in Florida & Contact Information
- Types of Care & Services
- Residential Facilities
- Paying for Care: Federal Funding
- Paying for Care: State Funding
- Insurance
- Resources

To apply for services, call 1-800-96-ELDER (1-800-963-5337) or contact your local Aging Resource Center.



PSA = Planning and Service Area

## 11 Planning and Service Areas (PSAs) in Florida and Contact Information

**PSA 1:** Northwest Florida Area Agency on Aging  
Serving Escambia, Okaloosa, Santa Rosa,  
and Walton Counties  
5090 Commerce Park Circle  
Pensacola, FL 32505  
850-494-7100  
[www.nwflaaa.org](http://www.nwflaaa.org)

**PSA 2:** Area Agency on Aging for North Florida, Inc.  
Serving Bay, Calhoun, Franklin, Gadsden, Gulf,  
Holmes, Jackson, Jefferson, Leon, Liberty, Madison,  
Taylor, Wakulla, and Washington Counties  
2414 Mahan Drive  
Tallahassee, FL 32308  
1-866-467-4624 or 850-488-0055  
[www.aaanf.org](http://www.aaanf.org)

**PSA 3:** Elder Options, the Mid-Florida  
Area Agency on Aging  
Serving Alachua, Bradford, Citrus, Columbia,  
Dixie, Gilchrist, Hamilton, Hernando, Lafayette,  
Lake, Levy, Marion, Putnam, Sumter, Suwannee,  
and Union Counties  
5700 S.W. 34th St., Suite 222  
Gainesville, FL 32608  
352-378-6649 or 1-800-262-2243  
[www.agingresources.org](http://www.agingresources.org)

**PSA 4:** ElderSource, Area Agency on Aging  
for Northeast Florida  
Serving Baker, Clay, Duval, Flagler, Nassau,  
St. Johns, and Volusia Counties  
4160 Woodcock Drive, 2nd Floor  
Jacksonville, FL 32207  
904-391-6600 or 1-888-242-4464  
[www.myeldersource.org](http://www.myeldersource.org)

**PSA 5:** Area Agency on Aging of Pasco-Pinellas  
Serving Pasco and Pinellas Counties  
9887 4th Street North, Suite 100  
St. Petersburg, FL 33702  
727-570-9696, Fax 727-570-5098  
[www.agingcarefl.org](http://www.agingcarefl.org)

**PSA 6:** West Central Florida Area Agency on Aging, Inc.  
Serving Hardee, Hillsborough, Highland,  
Manatee, and Polk Counties  
5905 Breckenridge Pkwy., Suite F  
Tampa, FL 33610-4239  
813-740-3888  
[www.agingflorida.com](http://www.agingflorida.com)

**PSA 7:** Senior Resource Alliance  
Serving Brevard, Orange, Osceola,  
and Seminole Counties  
988 Woodcock Rd., Suite 200  
Orlando, FL 32803  
407-514-1800  
[www.seniorresourcealliance.org](http://www.seniorresourcealliance.org)

**PSA 8:** Senior Choices, Area Agency on  
Aging of Southwest Florida  
Serving Charlotte, Collier, Desoto, Glades, Hendry,  
Lee, and Sarasota Counties  
15201 N. Cleveland Avenue, Suite 1100  
North Fort Myers, FL 33903  
239-652-6900  
[www.aaaswfl.org](http://www.aaaswfl.org)

**PSA 9:** Area Agency on Aging of Palm  
Beach/Treasure Coast, Inc.  
Serving Indian River, Martin, Okeechobee,  
Palm Beach, and St. Lucie Counties  
4400 N. Congress Avenue  
West Palm Beach, FL 33407-3226  
561-684-5885  
[www.youragingresourcecenter.org](http://www.youragingresourcecenter.org)

**PSA 10:** Aging and Disability Resource  
Center of Broward County  
Serving Broward County  
5300 Hiatus Road  
Sunrise, FL 33351  
954-745-9567  
[www.adrcbroward.org](http://www.adrcbroward.org)

**PSA 11:** Alliance for Aging  
Serving Miami-Dade and Monroe Counties  
760 NW 107th Avenue, Suite 214  
Miami, FL 33172-3155  
305-670-6500  
[www.allianceforaging.org](http://www.allianceforaging.org)

## Finding Care

**Florida Department of Elder Affairs (DOEA)** – State Unit on Aging that provides funding and oversight to local providers of services at a program or into the home of older people. Houses the Alzheimer’s Disease Initiative (ADI) which offers respite care or day care for a person diagnosed with Alzheimer’s disease or a related disorder. ADI network throughout Florida includes 15 Memory Disorder Clinics/Centers and the Florida Brain Bank. (<http://elderaffairs.state.fl.us>)

**Area Agency on Aging** [also known as AAA or Triple A or Aging Resource Center (ARC) or Aging & Disability Resource Center (ADRC)] – Agency designated by the Florida Department of Elder Affairs to provide planning and oversight of local service providers in the 11 Planning and Service Areas (PSAs). Agencies may be known by different names in each locality and generally serve several Florida counties. ([www.AgingResourceCentersOfFlorida.org](http://www.AgingResourceCentersOfFlorida.org).)

### **Elder Helpline (1-800-96-ELDER or 1-800-963-5337)**

- Information and referral information about services for older adults and caregivers. This Florida statewide re-routes phone number connects callers, based on the area code of the caller’s phone, to the Elder Helpline office closest to that area code.

**Lead Agency** – Agency designated by the Area Agency on Aging to develop contracts with local vendors to provide direct services to the older adults in the community that they serve. Services vary by area.

**911** – Phone number for emergency services such as for an ambulance, fire, etc., and to report a missing person who has a diagnosis of Alzheimer’s disease or related disorder (see also Silver Alert).

**211** – Phone number of information call-in center available in many local communities to provide general information regarding services for all ages.

## Types of Care and Services

**Care Manager** – Person employed to assess the older person’s needs, coordinate services, manage appointments, and oversee any activities necessary to maintain safety. Services may be long-term or short-term and are generally paid for privately.

**Chore Service - Light** – Service to provide a more thorough cleaning of home, generally provided seasonally.

**Chore Service - Heavy** – Service for serious cleaning needed for a person’s home. Generally takes a team of workers.

**Companion Services - Homemaker/Sitter** – A person, who offers supervision, prepares light meals and completes light cleaning and laundry, may accompany client out for social or recreational activities; may also shop. The companion does not provide hands-on assistance, i.e., bathing, dressing, etc. Not covered by Medicare; some subsidies available.

**Congregate Meals** – Meals provided in a congregate setting, such as a senior center or church/place of worship, to encourage nutritional health and social interaction.

**Home Delivered Meals** – Nutritionally balanced meals delivered to a person’s home for those homebound or unable to prepare meals on their own.

**Daycare at Adult Day Care Program (ADC)** – Activity program designed to provide social interaction in a structured, supervised, daytime setting for older people who live at home with a caregiver; some financial subsidies available.

**Daycare at Adult Day Health Care Program (ADHC)** – Activity program designed to provide some simple health care services such as giving prescribed medicine or monitoring blood pressure, and provide social interaction in a structured, supervised, daytime setting; some financial subsidies available.

**Emergency Alert Response Service (EARS)** – Emergency response system using phone lines to provide assistance to persons with special needs in emergency situations; registration required; private pay with some sliding fees available.

**Personal Care -Home Health Aid(HHA)/Certified Nursing Assistant(CNA)/Personal Care Attendant (PCA)** – A person trained to offer assistance with personal care, bathing, dressing, toileting, and continence aids. Service may be covered short term by Medicare in conjunction with in-home skilled care.

**Respite** - Service designed to provide rest or relief for the caregiver, may be in the form of companion/sitter, day care, overnight supervision, or short-term stay in an assisted living facility or nursing home/rehab facility; not covered by Medicare; some subsidies available.

**Senior Center** – Place where congregate dining, educational, social, and/or recreational activities are provided for seniors.

**Serving Health Insurance Need of Elders (SHINE)** – Free program of trained volunteers who provide insurance counseling relating to Medicare, Medicaid, Supplemental, and Long-Term Care insurance to older adults and caregivers.

**Silver Alert** – Program to find missing person with a diagnosis of Alzheimer’s disease or a related disorder who has driven off in a motor vehicle or lost on foot, does not return home at the expected time, and cannot be found. Caregiver calls 911 to report missing person. Law enforcement can activate the program to start the search, including contacting the media, activating highways signs, etc.

## Residential Facilities

**Assisted Living Facility (ALF)** - Licensed residential facility to provide supervision of medicines, daily activities, meals, social interaction, transportation; services vary among facilities. Some offer special Memory Care Units for people diagnosed with Alzheimer’s disease or related dementia; others have special licenses to provide extended care or mental health services. Facility not covered by Medicare.

**Intermediate Care Facility (ICF)** - Licensed medical facility to provide long-term care including supervision of medicines, 24-hour nursing care, and assistance with activities of daily living. Services vary among facilities; for example, some offer special Memory Care Units for people diagnosed with Alzheimer’s disease or related care. May be covered short term by Medicare (see SNF just below) or long term by private pay or Medicaid.

**Skilled Nursing Care Facility (SNF)** - Licensed residential facility to provide skilled nursing and rehabilitative care. Some offer special Memory Care Units for people diagnosed with Alzheimer’s disease or related care. May be covered short term by Medicare for rehabilitation.

## Paying For Care: Federal Funding

**Emergency Home Energy Assistance for the Elderly (EHEAP)** – Financial assistance to low-income households experiencing home energy emergency (i.e., heating or cooling). Contact Elder Helpline or [www.elderaffairs.org/does/eheap.php](http://www.elderaffairs.org/does/eheap.php).

**Older Americans Act (OAA)** – The Older American’s Act of 1965 provides funding to each state for a variety of supportive services including: senior centers, nutritional programs, in-home care, transportation, etc. Services are available to those age 60 and older; preference is given to those with the greatest economic or social needs. Contact Elder Helpline at 1-800-96-ELDER (1-800-963-5337) for more information and eligibility criteria.

**Medicaid** – Federal and State insurance coverage for the medically indigent. Medicaid can pay for long-term care services if the individual is at risk for nursing home placement. This is determined by the CARES nurse who assesses the individual in their home or wherever they might be when need for Medicaid coverage for long-term care arises.

**Medicaid Waiver Aged & Disabled Adult/Home and Community-Based Service Program (ADA/HCBS)** – Supportive services for those who are functionally impaired and at risk for nursing home including: day care, case management, in-home care, emergency alert response, consumable medical supplies, etc.

**Medicaid Assisted Living Waiver (AL or ALW)** – Provides funding for eligible individuals to pay for Assisted Living Facility for those at risk for nursing home placement.

**Nursing Home Diversion Program** – Provides community-based services through private managed care providers for individuals who would otherwise qualify for Medicaid nursing home placement.

**Veterans Administration** – Aid and Attendance/Veterans Disability Pension available to pay for care assistance for eligible veterans and their widows/widowers.

## Paying For Care: State Funding

**Alzheimer's Disease Initiative (ADI)** – Provides case management, respite care or day care for a person with a medical diagnosis of Alzheimer's disease or a related disorder regardless of age. ADI network throughout Florida includes 15 Memory Disorder Clinics/Centers, the Florida Brain Bank, and model adult day health care programs.

**Community Care for the Elderly (CCE)** – Provides community-based services to functionally impaired individuals age 60 and older to enable them to remain at home. Includes adult day care, case management, in-home care, home delivered meals, transportation etc.

**Home Care for the Elderly (HCE)** – A basic subsidy (approximately \$106/mo) provided for family members who provide live-in care for those age 60 and older who might otherwise be in a nursing home.

## Insurance

**Long-Term Care Insurance** – Private insurance plan that may cover certain long term care expenses such as in-home care, day care, assisted living or nursing home when a person meets criteria of the policy. Coverage and policy limits vary.

**Medicaid** – Insurance program provided through a partnership of state and federal government to provide for the “medically indigent.” Eligibility is determined by the Department of Children and Families (DCF).

**Medicare** – Insurance program that provides basic coverage for medical services. Co-pays and deductibles paid by individual. Medicare A covers hospital charges; Medicare B covers outpatient medical visits; Medicare C is the managed care (HMO) option; and Medicare D covers medication. Medicare DOES NOT COVER long-term care services such as in-home sitter, nursing home, or assisted living facility.

**Medigap Insurance** – Insurance coverage for some of co-payments and deductibles not covered by Medicare A and B provided by private insurance companies; costs vary.

## Resources

**Aging Resource Center/Elder Helpline** – Information & referral statewide 1-800-963-5337; 1-800-955-8771 TDD; Voice 1-800-955-8770

**Alzheimer's Association** – Provides 24-hour helpline, support groups, educational programs, newsletter, lending library, speakers' bureau, personal consultations, Safe Return Identification Program etc. Programs vary by location. 1-800-272-3900, [www.alz.org](http://www.alz.org).

**Department of Children & Families (DCF)** – Accepts applications for financial assistance programs such as food stamps and Medicaid, including Medicaid coverage of long-term care services.

