

## **ALZHEIMER'S DISEASE AND OTHER DEMENTIAS MODULE**

A training program  
for caregivers, personal  
attendants and direct  
support professionals.

The Arizona Direct Care Curriculum Project

*June 2008*

## Acknowledgments

The *Principles of Caregiving* training manuals were created with guidance from the Arizona Direct Care Workforce Committee (formerly the Core Curriculum and Expansion Committee) to help establish a high-quality training program for direct care and direct support professionals in Arizona. Many individuals and agencies were involved, but special gratitude goes to the Arizona Bridge for Independent Living (ABIL), AIREs, the Foundation for Senior Living, the Children and Family Alliance, the Alzheimer’s Association – Desert Southwest Chapter, and Phoenix College. The artwork for the cover was designed by Gateway Community College. For more information about the curriculum project, please visit <http://www.azdes.gov/aaa/directcare.asp>.



The Direct Care Curriculum Project is a partnership between the Arizona Department of Economic Security, the Arizona Department of Health Services, the Arizona Health Care Cost Containment System, the Governor’s Council on Developmental Disabilities, and the Core Curriculum and Expansion Committee.

The opinions expressed in this material do not represent the official positions of these agencies.



*Principles of Caregiving* includes the following modules. Each module consists of a trainer manual, a student manual, and a slide presentation.

Caregiving Fundamentals  
Aging and Physical Disabilities Module  
Developmental Disabilities Module  
Alzheimer's Disease and Other Dementias Module



**Arizona Direct Care Curriculum Project,  
*Principles of Caregiving.***

This material was created for educational purposes by the Arizona Direct Care Curriculum Project. For more information about the curriculum project, please visit <http://www.azdes.gov/aaa/directcare.asp>.

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## Preface to the *Principles of Caregiving*

### **The Arizona Direct Care Curriculum Project:**

#### **The Development of Standardized Direct Care Professional Training in Arizona**

The need for home and community-based caregiving is one of the most compelling issues of our time. It will affect nearly every family in America. In order to be ready to meet the increasing demand for home and community-based services, Arizona must develop a capable and compassionate workforce of caregivers. We are clearly moving in that direction with the support of Arizona's policy makers and service providers. We are preparing to meet these challenges by creating tools and resources to assist in developing an adequate supply of qualified and well-trained long-term care workers, including caregivers, personal attendants, and direct support professionals.

In 2002, Arizona passed legislation to increase the wages of these direct care professionals, thereby recognizing the importance of the long-term care workforce. At the same time, the Senate Ad Hoc Committee on Caregiver Wages and Workforce Development was established. The purpose of the Committee was to define critical policy concerns and emerging issues regarding long-term care and caregivers. In addition, the committee was to develop cost-effective strategies to promote and encourage caregiver workforce development that would support and strengthen family and informal caregiving as a key component of long-term care.

In 2004, Governor Janet Napolitano appointed the Citizens Work Group on the Long-Term Care Workforce (CWG) to further develop and provide recommendations for improving the quality of the long-term care workforce. The CWG identified guiding principles for the development of an improved and enhanced direct care workforce, to include: 1) promotion of person-centered care practices, 2) recognition of the value of the direct care worker, and 3) assurance of access to care and quality of care in long-term care settings.

In 2005, the CWG laid out ten recommendations. One called for the implementation of a standardized, uniform, and universal training curriculum for the direct care workforce. Complimentary specialty modules would include skills and knowledge to work with the elderly and individuals with physical disabilities, developmental disabilities, dementia and Alzheimer's Disease, and behavioral health disease.

With the continued support of Governor Napolitano, the CWG is currently serving as the Core Curriculum and Expansion Committee of the Interagency Council on Long-Term Care (IACLTC) to further develop and disseminate the core curriculum and modules statewide. The committee will oversee the development of additional modules, create a quality assurance component, monitor implementation throughout Arizona and continue to develop additional recommendations to ensure success of the direct care professional and the quality of care in our communities.

Special thanks to Dick White of Valley Interfaith Project and Kathleen Collins Pagels of the Arizona Health Care Association, who have diligently co-chaired these work groups. In addition, we owe special thanks to the agencies that developed the training curriculum, including Arizona Bridge to Independent Living (ABIL), Foundation for Senior Living (FSL), AIREs, the Children and Family Alliance, the Alzheimer's Association – Desert Southwest Chapter, and Phoenix College. Funding for the Direct Care Curriculum Project was provided by the Department of Economic Security, Division of Aging and Adult Services, and the Governor's Council on Developmental Disabilities.

## **Introduction to the Alzheimer's Disease and Dementia Module**

For this module: "Principals of Caregiving, Alzheimer's Disease and Other Dementias" representatives of residential care, home and community based care, experts in the fields of communication, behavior, and activities contributed significantly. These individuals, who volunteer for the Alzheimer's Association and work on the front line of caregiving every day, represent the latest thinking in "best practice" care and treatment of individuals with Alzheimer's disease and other forms of dementia. The curriculum was developed with the understanding and appreciation of the growing sense of urgency in making it available to as many caregivers, including both professionals and volunteers, in the shortest period of time possible. Further, it was the understanding of the contributing authors that its development was a response to the growing need for this information to be shared with the existing aging care network as well as to train new caregivers as part of the Arizona Direct Care Curriculum Project. It is the hope and expectation of the contributors to this document that it will be used for the purposes intended. Those purposes are to: (1) improve the quality of life for those under our care with Alzheimer's disease and other forms of dementia, and (2) reduce caregiving induced stress and increase job satisfaction for both professional and volunteer caregivers. The content of this curriculum should be viewed in its entirety. The concepts and information included in the curriculum are interrelated and serve as a web of knowledge and skill to ensure the highest quality of life possible for those for whom it was written. To omit or weaken any of the strands of the web may cause the curriculum to lose its impact and the care net to lose its strength in achieving its intended purposes.

Alzheimer's Association, Desert Southwest Chapter  
Central Arizona Region  
Phoenix, Arizona  
December 2007

# Principles of Caregiving Alzheimer’s Disease and Other Dementias

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## Welcome Caregivers!

We are glad that you have chosen to participate in a unique training program for working with a special group of people – those individuals suffering from Alzheimer's Disease and related dementia.

You will have ample opportunity to learn about the nature of dementia, how to provide a safe and comfortable environment, handle difficult behaviors and provide support to the families.

This course is 12 hours long, divided into seven main sections:

- Defining Dementia and Alzheimer's Disease
- The Philosophy & Values in Dementia Care
- Communicating with the Person with Dementia
- Dealing with Dementia-Related Behaviors
- Activities of Daily Living
- Activities
- Legal and Financial Planning for Families

Your instructors are chosen because of their skill, knowledge and experience in the care of persons with dementia. If you have any questions about anything you will read in this book or hear in your class, ask your instructors. They are a valuable resource.

We hope that you will enjoy the opportunity to apply what you learn in this course to your daily experience as a caregiver.

### A Note on the Principles of Caregiving Curriculum

*Principles of Caregiving* is a training curriculum that consists of Fundamentals and three modules. The Fundamentals piece contains the material most likely needed by most direct care and direct support professionals, regardless of the service setting. There are three modules that build on the Fundamentals: Aging and Physical Disabilities, Developmental Disabilities, and Alzheimer's Disease and Other Dementias.

When this curriculum was created, it was the intention that direct care workers would complete the Fundamentals and one additional module. Depending on the needs of your employer and the persons needing care, you may not need all the knowledge and skills presented in this curriculum. However, we would encourage you to study the whole program. The *Principles of Caregiving* curriculum is designed to provide a well rounded introduction to caregiving and direct supports, and you will be prepared to work in a variety of settings.

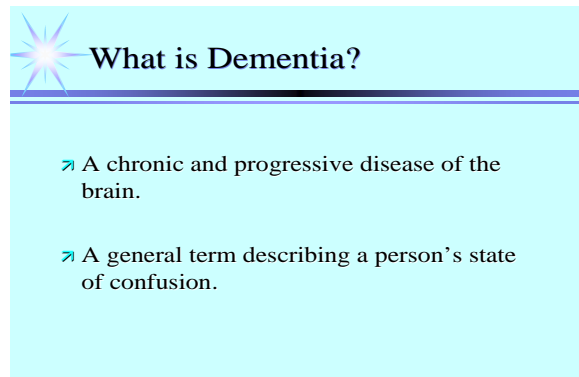


## SECTION I - DEFINING DEMENTIA AND ALZHEIMER'S DISEASE

The purpose of this section is to introduce the person with dementia and to set a context for caring for those who have Alzheimer's disease - a disease of the brain that forever changes a person's memory, behavior and ability to care for oneself.

### Objectives:

1. Describe how an irreversible dementia, such as Alzheimer's disease (AD), affects a person's memory, language, movement and speech.
2. Distinguish between different types of dementia and the symptoms associated with each type.
3. Identify the characteristics of each phase of AD, from the mild phase to the severe phase.
4. Discuss treatment of Alzheimer's disease and related problems.



Dementia refers to a spectrum of brain disorders. These involve difficulty with memory and thinking, but they may vary in terms of cause, course and prognosis.

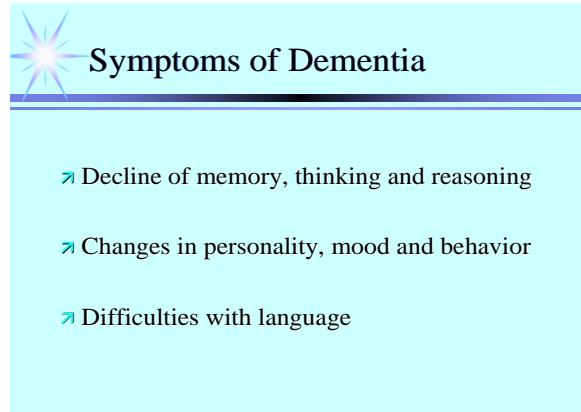
Dementia involves impairment in multiple facets of cognition. This can include visual spatial skills, the ability to think, reason, talk and remember, and praxis functions. Personality and mood may also be affected.

### **Dementia is not a normal part of aging!**

Although we hear people suffer from dementia or are diagnosed as having dementia, dementia itself is not the diagnosis. We need to identify the type of dementia and the causes, some of which may be reversible, but most of which are incurable.

Alzheimer's disease is the most common cause of dementia. It is an irreversible, progressive disease. It causes gradual deterioration of mental functions and of the ability to take care of one's self.

## A. Symptoms of Dementia:



- Decline in memory, thinking and reasoning.
- Changes in personality, mood and behavior.
- Difficulties in the ability to communicate, to recognize people and places, and to engage in activities.

This can include:

- Forgetfulness and less effective at work/home
- Forgetting names or appointments.
- Difficulties with familiar activities
- Language problems
- Problems with spatial and temporal orientation
- Impaired judgment
- Problems with abstract thinking and calculating
- Misplacing or losing things
- Mood swings and behavioral changes
- Personality changes
- Loss of initiative
- Dealing with daily life becomes very difficult
- Short term memory is most affected

## B. Causes of Dementia

Alzheimer's disease is the most common cause of dementia. It is progressive and not reversible. Some dementias are reversible, with the person's confusion potentially returning to his or her normal state. When the underlying medical or psychiatric problem is successfully treated, the symptoms of dementia disappear.

Some dementia is treatable, or reversible, when the cause is:

- Inadequate fluid intake leading to dehydration.
- Acute infections, for example a urinary tract infection.
- Chronic condition that has gotten out of control, for example:
  - Hypothyroidism
  - Diabetes
- Psychiatric conditions
- Reaction to medication.

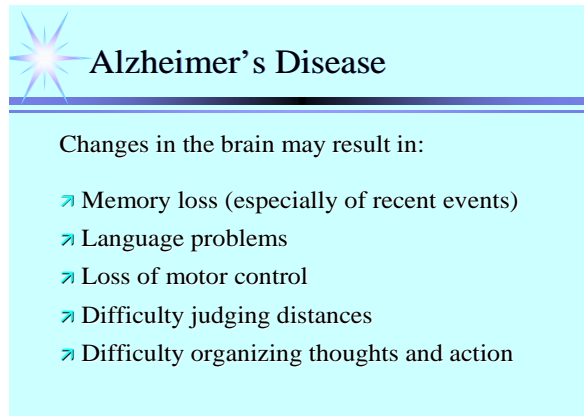
Early recognition and diagnosis is important!

Key is to identify risk factors and/or possible reversible causes of mental confusion.

*A dementia work-up* includes careful review of *medical history, medications, and* the course of symptoms; cognitive/ memory testing; physical and neurological examinations; labs and imaging studies to eliminate any other possible cause for symptoms.

When potentially reversible causes of memory changes or confusion have been ruled out, then the dementia may be attributed to any number of neurodegenerative causes. Most of the cases are Alzheimer's, but there are many other fairly common types of dementia.

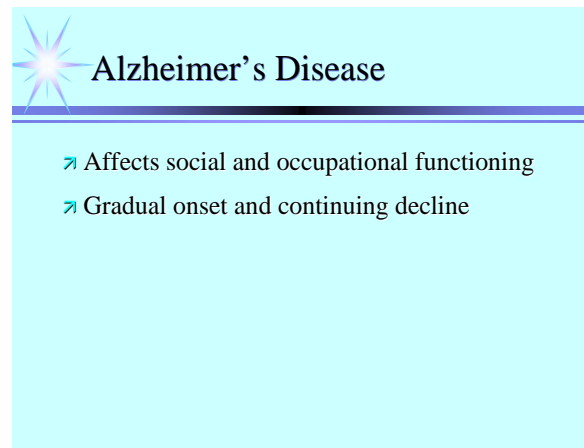
## C. Alzheimer's Disease



**Alzheimer's Disease**

Changes in the brain may result in:

- Memory loss (especially of recent events)
- Language problems
- Loss of motor control
- Difficulty judging distances
- Difficulty organizing thoughts and action



**Alzheimer's Disease**

- Affects social and occupational functioning
- Gradual onset and continuing decline

- Alzheimer's is by far the most common type of dementia, approximately 2/3 of cases.
- It was first identified 100 years ago by Dr. Alois Alzheimer.
- Onset is slow and insidious (subtle), followed by a gradual decline.
- Changes in short term memory are noticeable, i.e. memory of recent events. This is typically the primary first complaint.
- Disease progression can last 3-20 years from the onset of symptoms.
- Risk factors include:
  - Aging: increased risk after age 65. By age of 85 or more, there is a nearly 50% risk of getting the disease.
  - Female gender
  - Genetics
- Earlier onset (before age 65) appears to progress more rapidly.
- Changes in brain include death of brain cells, brain atrophy/shrinking, presence of abnormal protein (amyloid) plaques and neurofibrillary tangles. Some of this can be determined with magnetic resonance imaging (MRI).
- Thorough work up and diagnosis is up to 90% accurate, although autopsy remains the conclusive way to make diagnosis.

- Over 50% of persons affected with Alzheimer's disease develop mood or behavioral disturbances.
- Caregiver stress is a significant issue.
- Research is ongoing to identify avenues for detection, prevention or treatment.
- There are some medications on the market (e.g., Aricept, Exelon, Razadyne, Namenda) that delay the rate of cognitive decline, but do not cure Alzheimer's disease. Other medications are used to treat associated symptoms of Alzheimer's.

**Cold hard facts about the impact of Alzheimer's disease:**

- 5 million persons in US are living with AD. This number is expected to grow to as many as 16 million by mid-century.
- 200,000-500,000 people under the age of 65 live with early onset AD.
- Alzheimer's is the 7<sup>th</sup> leading cause of death, 5<sup>th</sup> leading cause for those over 65.
- Direct and indirect costs of AD and other dementias amount to \$148 billion/year.

**D. Vascular, or Multi-infarct, Dementia**

- Vascular, or multi-infarct, dementia is the second most common cause of dementia, estimated to be 20% of cases.
- It is caused by reduced blood flow to parts of the brain, often due to tiny strokes blocking small arteries.
- Diagnosis is contingent upon findings of stroke on imaging, presence of stroke risk factors and establishing link between the dementia and the cerebral vascular disease.
- Onset of symptoms may seem more sudden and clearer, and memory may or may not be as seriously affected as in Alzheimer's. This can depend on whether blockage has occurred in the memory regions of the brain.
- Gait disturbance and urinary incontinence may be early signs.
- Family may report a step-like progression in disease process (in contrast to the gradual progression of Alzheimer's disease)
- It is possible to have mixed dementia – both AD & Vascular (estimated 30% cases).

**E. Fronto-temporal Dementia**

- This is characterized by significant personality and behavioral changes and significant loss of language function early. This is different from the memory complaints typical for Alzheimer's.
- It may represent 10-15% of dementia cases
- Nearly half of these cases occur in people under 65 years of age
- It is distinguished from AD by some or all of following: inappropriate and anti-social behaviors, apathy, compulsions, relative preservation of visual spatial and cognitive skills; language deficits progressing to mutism.
- Changes in the brain include shrinkage in the frontal and temporal lobes of the brain, which can be seen on PET scans.
- As with AD, autopsy is the definitive means of diagnosis.

## F. Lewy Body Dementia

- This is similar to Alzheimer's disease, but often more characterized by early changes in movement or the development of extra pyramidal symptoms. This includes tremors, tics, rigidity, shuffling gait, etc., which can make individuals look like they have Parkinson's disease.
- It is also characterized by the early development of hallucinations and delusions in addition to memory loss.
- Alertness and severity of cognitive symptoms may fluctuate significantly on a day to day basis.
- There is often a poor tolerance to medications as well as autonomic nervous system dysfunction. An example would be wild swings in blood pressure.
- The brain has abnormal protein deposits called Lewy bodies.

## G. Less Common Progressive Forms of Dementia

### Parkinson's disease

- Parkinson's is characterized by tremors, stiffness, speech difficulties and problems initiating movement.
- When muscle stiffness affects the face, the person may have a mask-like stare.
- Persons with Parkinson's may develop dementia late in the course of the disease.
- A clear sign of Parkinson's is the presence of Lewy bodies (abnormal proteins) specifically in the area of the brain that controls movement.  
(Note: Lewy bodies occurring in other areas of the brain cause Alzheimer's or Lewy Body type dementia; see section F.)

### Huntington's disease

- An inherited degenerative and fatal brain disease starting in mid life, involving personality changes, depression, and the development of involuntary movements.

### Creutzfeldt - Jakob disease

- A rare and rapidly fatal brain disorder that causes rapid, progressive and fatal dementia.
- It affects coordination and causes behavior changes.
- It is caused by an abnormal protein (called prion) that turns normal proteins into infectious ones. This disease is related to mad cow disease.

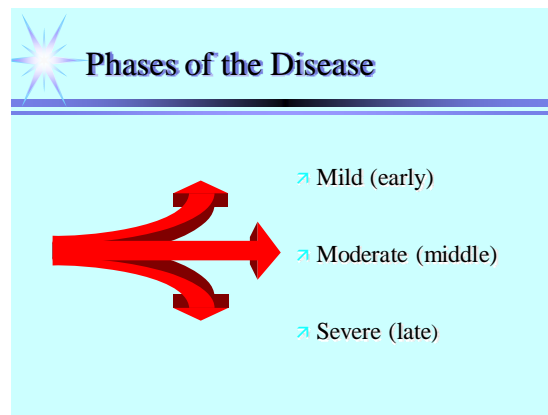
### HIV dementia

- Direct infection of the brain with toxic viroproteins is believed to cause dementia in 20-30% of people with advanced HIV, and 50% of those with fully developed AIDS.
- Initial signs are poor concentration, forgetfulness, depression and apathy, weakness and myoclonus (sudden, involuntary twitching of muscles).

**Note: The diagnosis of Alzheimer's disease (AD) is used as a reference point from here forward for two reasons. First, AD is by far the most common form of dementia. Second, AD has a more clear-cut pattern and predictability than other forms of dementia.**



## H. Stages of Alzheimer's Disease:



### EARLY or MILD

- The early stage lasts for two to four years.
- It is characterized by forgetfulness, increasing difficulty with executive function (for example, problem solving), withdrawing from activities, and mood or personality changes.
- The person with AD forgets whole experiences, rather than details (like names).
- The person may need minor assistance or reminders, but may live alone.
- Efforts to hide the confusion are sometimes successful at the earliest stage of the disease.

### MIDDLE or MODERATE

- The middle stage lasts for two to ten years.
- In the middle stage, the confusion is apparent to caregivers. The person may be aware of his/her impairment, but lacks the ability to hide it from others.
- Characterized by increase in memory loss and confusion, shorter attention span, increase in language difficulties and in repetitiveness.
- There is full loss of executive function (i.e. reasoning or problem solving) and difficulty taking care of self. The person may need help with activities of daily living (ADL's), such as dressing and bathing.
- As tasks become more challenging, both physically and cognitively, the person may become delusional, paranoid, and develop associated behavioral changes.
- Optimizing physical, mental and social stimulation is key to slowing rate of decline into next stage.
- Constant supervision is needed. The person shows poor judgment needs and cannot live alone for safety reasons.

- At this time, patients are often placed in adult day care programs and/or assisted living.
- Toward the end of the middle stage the person loses the ability to control bladder and / or bowel function.

### **LATE, END STAGE, or SEVERE**

- The late stage is a time of severe confusion and loss of all functional skills. The person has no awareness of his/her condition.
- The person has loss of self-care ability and loss of language, is incontinent and unable to recognize self or others, and requires more sleep.
- Other signs include weight loss, despite good diet; possibly swallowing problems, and general failure to thrive.
- The individual responds best to sensory activities and cannot be in crowded or noisy environments.
- Typical for this stage are care in dementia care units/ nursing homes with 24-hour supervision and assistance.
- The final stage lasts for one to three years and ends in death.

## **I. Associated Problems with Alzheimer's Disease**

### **Behaviors**

Behaviors can include agitation, psychosis, sundowning, and hypersexuality. These will be discussed in much greater length in the behavior section of this training program (section IV).

- Behaviors are a response to discomfort, an unmet need, and increasing confusion.
- They also reflect an increase in difficulty with communication, progressive loss of independence, and poor insight and judgment.
- Key to reducing behavioral disturbances is to identify triggers. These include pain, fatigue, acute illness, sensory deficits, hallucinations and/or delusions.
- Behaviors may be ***psychomotor*** (pacing, wandering, repeated crying out, etc.), ***verbal*** (belligerence, nastiness towards others, repetitiveness) and/or ***physical*** (combativeness, often associated with personal care; inappropriate touching).
- Persons may be very volatile or explosive in nature

### **Emotional or Mood Disturbances**

- Depression: may reflect as irritability, fearfulness, or tearfulness, hopelessness, somatic complaints (i.e. feeling ill physically), lack of energy and/or interest, change in appetite.
- Anxiety: includes feelings of nervousness, worry and apprehension. This is more common in early dementia when the persons with dementia (PWD) are aware of their deficits.
- Apathy: a flatness of mood that can occur in later stages. It represents the inability to interact within one's environment on one's own.

### **Sleep Disturbance**

- Occurs in 50% of community-dwelling PWDs. It is one of the most disturbing behaviors for caregivers and can cause exhaustion and despair in caregivers.
- PWD may have trouble falling or staying asleep, or with resuming sleep. Persons may wander, may reverse night and day, appear more confused; and/or may have exacerbation of anxiety, physical or verbal outbursts

### **Delirium**

- Sudden increase in mental confusion, accompanied by hallucinations.
- **Reversible.** The confusion is a signal that there is an acute medical condition.
- Older people suffering from delirium while hospitalized are thought to be at a greater risk of developing Alzheimer's disease; and PWD are at greater risk of developing delirium when hospitalized.

### **Caregiver stress/burden**

- Increased risk for depression, health and physical problems for the caregiver.

## J. The Treatment of Alzheimer's Disease and Associated Problems

This section focuses on medications since later discussion will address other, non-pharmacological interventions.

### **Cognitive changes:**

The following medications **may slow but not prevent decline**. They may have some positive effect on mood and behavior as well

- *Aricept, Exelon, Razadyne*: Indicated for mild dementia, used throughout the course of the disease. Side effects are mainly gastro-intestinal (GI) in nature, minimized by giving in morning with food. There may also be vivid dreams or leg cramps.
- *Namenda*: Indicated for moderate dementia, used either alone or together with one of three medications previously noted.
- Other medications are being tested in clinical research trials, some of which may have promise in further addressing cognitive symptoms of Alzheimer's disease

### **Mood:**

- Antidepressants of the class known as Selective Serotonin Reuptake Inhibitors (SSRI) are generally best tolerated. They address depression and anxiety.
- Medications such as tricyclics (for example, *Elavil*) and benzodiazepines (such as *Lorazepam* or *Valium*) should not be used because of the potential for increased confusion and dizziness and the increased risk for falls with potential injury.

### **Behavior:**

- Atypical antipsychotics (such as *Seroquel, Zyprexa, Risperdal*) can be helpful, but they carry a concern for side effects. These can include movement disorders, increased confusion, and the potential for increased cardiac complications.
- Seizure medications (e.g., *Depakote*) may be given. Blood serum levels need to be closely monitored.

### **Sleep:**

- Avoid hypnotics, including drugs like *Benadryl*, because of the potential for increased confusion and a higher risk for falls.

### **Pain:**

- It is important to recognize and treat pain. This may require careful attention to body language and behavior
- Avoid medications like *Darvon*, percocet, and opioids.
- *Tylenol*, regularly dosed, is a very effective analgesic (pain medication).
- Consider options such as moist heat, massage, and repositioning.

General considerations in use of medications in the elderly and specifically those with dementia

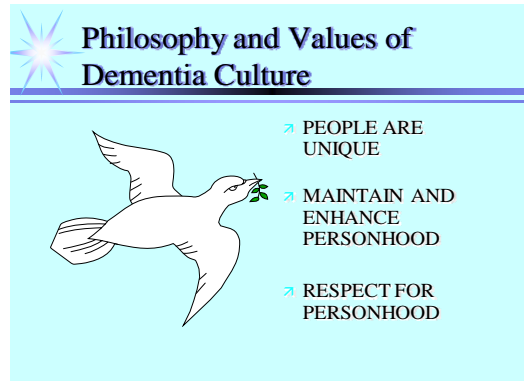
- Treatment should always be **tailored to the individual**.
- Identify **indications or target behaviors** for each medication.
- A team approach/input is critical whenever possible.
- **Employ strategies that do not require medications**, but medications can and should be considered when such strategies are ineffective or not effective enough.
- **Risks versus benefits** should be taken into consideration.
- The number of medications should be limited.
- **Start low**, go slow because elderly do not tolerate medications as well or in the same way as younger people.
- **Avoid medications with undesirable side effects**, those which can cause more confusion or sedation, or act counter to medications meant to benefit.
- Make **one change at a time** so that a clear cause and effect can be determined with a medication
- Identify **trends**. A rapid or sudden change in alertness, level of confusion or behavior may indicate a medical problem (such as an infection), but a trend or a gradual increase/decrease in symptoms may indicate a side effect or an inappropriate dosing of a medication.
- Typical side effects to watch for: Nausea , vomiting, change in appetite, diarrhea or constipation, headache, dizziness, postural instability, increased confusion, over sedation
- **Medication is for the PWD, not for staff convenience.**

### SECTION ONE QUESTIONS

1. Dementia is a normal part of aging.
  - a. True
  - b. False
  
2. Several factors cause dementia. Alzheimer's disease is one of these factors.
  - a. True
  - b. False
  
3. A dementia can be reversible if caused by the following:
  - a. Inadequate fluid intake leading to dehydration
  - b. Diabetes
  - a. Reaction to medications
  - b. All of the above
  
4. Parkinson's disease, Huntington's disease, and HIV dementia are:
  - a. Progressive forms of dementia
  - b. Reversible forms of dementia
  - c. All related to Alzheimer's disease
  - d. None of the above
  
5. Signs of early stage of Alzheimer's diseases are characterized by:
  - a. Forgetfulness
  - b. Gradual changes in personality and function
  - c. Successful efforts to hide confusion
  - d. All of the above
  
6. Pacing, wandering, repeated crying out, belligerence, nastiness towards others are all behaviors associated with Parkinson's disease
  - a. True
  - b. False
  
7. Sudden increase in mental confusion accompanied by hallucinations is a sign of:
  - a. Delirium
  - b. Mood disturbance
  - c. Emotional disturbance
  - d. None of the above

## SECTION II - THE PHILOSOPHY AND VALUES OF DEMENTIA CARE

This session is designed to provide an overview of the philosophy and values of good dementia care based on the following concepts:\*



- **PEOPLE ARE UNIQUE** and bring to the caregiving situation different perspectives and needs that shape the care environment.
- The essence of good dementia care is the **MAINTENANCE AND ENHANCEMENT OF PERSONHOOD** within this environment.
- This approach to caring involves having **RESPECT FOR THE PERSONHOOD** of those who have dementia and having equal respect for the personhood of those doing the work of caregiving.

### Objectives:

1. Explain the importance of relating to the dementia culture.
2. Using case simulations, enact communication techniques that are consistent with the dementia culture.

\* Based on the work of Tom Kitwood, Bradford Dementia Group, University of Bradford, UK; the Alzheimer Care Enrichment (ACE) course, National Alzheimer Association, USA; and the work of Joan Denmark Valenti, Dementia Care Trainer, USA. Permission to reproduce copyrighted themes/materials from Kitwood's work in this manual has been granted by Open University Press Publishers, August 2002.

## **A. An Alzheimer's Disease Bill of Rights**

Every person diagnosed with Alzheimer's disease or a related disorder deserves the following rights:

To be informed of one's diagnosis.

To have appropriate, ongoing medical care.

To be productive in work and play for as long as possible.

To be treated like an adult, not like a child.

To have expressed feelings taken seriously.

To be free from psychotropic medications, if possible.

To live in a safe, structured and predictable environment.

To enjoy meaningful activities that fill each day.

To be outdoors on a regular basis.

To have physical contact, including hugging, caressing, and handholding.

To be with individuals, who know one's life story, including one's cultural and religious traditions.

To be cared for by individuals who are well-trained in dementia care.

Source: Bell, V., Troxel, D. (1997). *The Best Friends Approach to Alzheimer's Care*. Baltimore: Health Professions Press, p. 38. Web site: [www.healthpropress.com](http://www.healthpropress.com); toll-free telephone: 1-888-337-8808; fax: 410-337-8539. Copyrighted material reprinted with permission from the publisher, July 2002.



**B. Establishing the Dementia Care Culture**

You may have heard or read about approaches to caring for persons with dementia (PWD). As our understanding of dementia gets better, we adopt better ways of helping PWD. The New Culture described here reflects those new insights. The New Culture of Dementia Care should replace the old concepts of the old culture.

Old Culture	New Culture
(1) Dementias are DISEASES of the central nervous system. Personality and identity are destroyed.	(1) Dementing illness should be seen as a form of DISABILITY. How a person is affected depends on the care received.
(2) The people with the best knowledge are DOCTORS and BRAIN SCIENTISTS.	(2) The people with the best knowledge are SKILLED AND INSIGHTFUL CAREGIVERS.
(3) Research is focused on a MEDICAL BREAKTHROUGH. Until that comes, there is not much we can do for the person with dementia.	(3) There is a great deal we can do through HUMAN CARING, INSIGHT AND SKILL. This is the most urgent matter for research.
(4) CAREGIVING is concerned with providing a SAFE ENVIRONMENT, meeting BASIC NEEDS, and giving competent PHYSICAL CARE.	(4) CAREGIVING is concerned with the MAINTAINANCE AND ENHANCEMENT OF PERSONHOOD. Providing a safe environment, meeting basic needs, and giving physical care are only part of the care of the whole person.
(5) It is important to understand the person's IMPAIRMENTS, especially those of cognition. The course of a dementing illness can be charted in stages of decline.	(5) It is important to understand the person's ABILITIES, tastes, interests, values and spirituality. There are as many manifestations of dementia as there are persons with dementia.
(6) PROBLEM BEHAVIORS must be MANAGED and changed skillfully and efficiently.	(6) So-called PROBLEM BEHAVIORS should be considered PRIMARILY as attempts to communicate. It is necessary to seek to understand the "message" AND MEET A COMFORT NEED.
(7) We should SET ASIDE our own concerns, feelings, and vulnerabilities and get on with the job of caregiving in a sensible, effective way.	(7) We should BE IN TOUCH with our concerns, feelings and vulnerabilities and use them as positive resources for our caregiving.

Adapted from Tom Kitwood in *Dementia Reconsidered: The Person Comes First*

### C. Define and Refine Terms and Language

**Personhood:** A standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies respect, recognition, and trust. Kitwood uses the terms "PERSON with dementia rather than person with DEMENTIA." He is committed to the idea that we all have value, "simply because we are, not because of what we have achieved, and not because of any use we might be to someone else." It is based merely upon our "presence in the world."

**Dementia:** "Dementia" is a clinical diagnosis of a chronic, progressive, deteriorating brain disease.

"dementia" is a symptom of many diseases marked by confusion and loss of short-term memory.

#### **Problem**

**Behaviors:** Combativeness, wandering and rummaging, physical restlessness, eating and sleeping problems, yelling, sexual behaviors. These must be seen primarily as attempts at communicating unmet individual needs, as well as manifestations of Alzheimer's disease on the brain. Additionally, the care environment may contribute to the behaviors. Caregivers may be as much of a problem as the disease!

**Culture:** A settled, patterned way of giving meaning to human existence in the world and giving structure within it. A culture contains specific reality, habits, sense of time, ethics, and language. While we refer to a new "culture" of care, it may also be said that there is a "culture" of dementia, just as there is a "culture" of the deaf.

#### **Communication:**

To share; to transmit information, thought, or feeling so that it is satisfactorily received or understood (Webster's Dictionary). Most communication is nonverbal. Everything is communication and communication is everything! The greatest communication skill of all: giving someone the message that you value them – by your attitude, by treating them with dignity, and by eye contact.

The foundation of successful interactions is the same with any population. High energy, passion, and enthusiasm are often effective communication aids: How you say it is more important than what you say.

**Reality:** The quality or state of being "real" (Webster's Dictionary). The question becomes: "Whose reality is it, anyway?" The answer, of course, is that it is the reality of the person with dementia into which we must enter! We are the ones who need reality orientation! Social psychologist Erving

Goffman talks about how each person creates his own reality and who can question it? For that moment, who can say whose reality is real?

**Activities:** Everything is an activity! Individual and group activities should provide opportunities for successes in a world of increasing disability.

**New Cultural Norms:**

**Cooperation** and **collaboration** instead of competition and conflict.  
Respect for and acknowledgment of caregivers' contribution.

## D. The Maintenance and Enhancement of Personhood

### EMPATHY AND COMPASSION

Empathy defined: an insightful awareness to share the emotions, thoughts, and circumstances of another person.

- Being fully present emotionally; "in the moment."
- Listening fully, without trying to "fix it."
- Being nonjudgmental (depression is not a "weakness").
- Respecting and affirming feelings ("anger" is not good or bad).
- Resist treating others as you wish to be treated ("golden rule").  
What is necessary for you may be uncomfortable for others.
- Empathy is not "sympathy," which implies agreement of feelings.

Compassion defined: to feel sorrow for the sufferings of others with the urge to help.

Acknowledging and addressing individual physical and emotional levels of comfort; this can apply to people with dementia, family members, and caregivers.

### RESPECT AND DIGNITY

Create opportunities for success, enhancement of self-esteem, and well being within the care environment – for people with dementia and their caregivers.

- Establish a sense of personal worth (we are valuable to others).
- Create a sense of empowerment (we can make things happen).
- Enhance social confidence (we can reach out to others and there will be a response).
- Instill a sense of hope (despite setbacks, life goes on).

## **INDIVIDUALITY AND AUTONOMY**

Self-Determination: become an “enabler” rather than a “controller”

- Provide opportunities for decision-making in activities.
- Allow some risk-taking within reason.

Self-Expression: relate to persons rather than problems

- Allow expressions of grief and joy, frustration and pain.
- Provide outlets for feelings and creativity through art and music.

## **INTERDEPENDENCE**

- Do ONLY what the person with dementia can no longer do, and no more – thereby allowing the person to retain life skills for as long as possible, providing nurturing and encouragement.
- Have reasonable expectations of people with dementia which allow reciprocity between them and their caregivers. This promotes the dignity of the individual and the relationship.

## E. Putting Yourself Inside Dementia

Imagine a future in which you are in your seventies or eighties and suffering from dementia. None of your family is able to care for you at home, and you have moved into residential care. In the present, you know yourself and your personal history very well. You know your own fears and hopes, the things that make you feel worthwhile and those that give you a lift. Use your knowledge about yourself as you are now to pick out the information which would help the people who care for you in this imaginary future to maintain your well-being as far as possible, given your dementia. What would you need to sustain your well-being?

1. Everyday tastes and habits: How could it help you feel more settled if your caregivers knew about them?
2. Your body and your health: What should they know?
3. Fears and past events – If they understood these, could they respond more sympathetically?
4. Interests and activities – How can they help you sustain your sense of personhood?
5. Still thinking of you as an older person with dementia. What do you most dread?
6. What is your greatest hope?

Source: BRADFORD DEMENTIA GROUP, Bradford, England. Permission to reproduce copyrighted themes/materials from Kitwood's work in this manual has been granted by Open University Press Publishers, August 2002.

## F. Rules for Visiting the Culture of Dementia

- 1. Be “present” in the moment; be fully attentive**  
When you do these things, you satisfy the need sooner and won't have to repeat the process as often.
- 2. Recognize the uniqueness of each person**  
Know something about each personality – each life.
- 3. Draw out each person's remaining abilities**  
Help to encourage and maximize them.
- 4. Communicate on a feeling level**  
Validate their feelings and we validate them. Feelings are real even if events are not.
- 5. Assume words and actions have meaning. Try not to see them only as “problem behaviors”**  
Try to find hidden meanings.
- 6. Nourish attachments between people with dementia and caregivers as well as among people with dementia**  
We all need to socially bond in order to feel our personhood.
- 7. Promote interdependence**  
Do only what they can't do on their own and no more. The decline of people with dementia is compared to the growth of children – like the reversal of childhood. Both need nurturing and encouragement.

**Caregivers need to also give care to themselves. Those of us who are growing and flourishing as “persons” will be best equipped to be sensitive caregivers.**

Source: BRADFORD DEMENTIA GROUP Bradford, England  
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## G. Considering Cultural Diversity in Care

It is important to consider the cultural diversity of the patients we care for. Cultural competence is a big component of efficient care. There are steps that the care giver can take to provide culturally sensitive dementia care:

- It is important to consider each patient as an individual and to be sensitive to their background, religion, family, culture, language and everything that makes the patients who s/he is. The whole person is to be considered.
- A care giver should consider what could make the care difficult: language, social behavior, and economics. It is preferential to provide the care in the patient's language.
- Many cultures use alternative medicine modalities such as Medicine Man in the Native American Culture, traditional Chinese Medicine in some Asian Culture, Ayur-Veda for Hindus.
- Do not generalize. Belonging to an ethnic group does not mean adopting the culture and beliefs of that group. There is not just one approach to an entire group. Remember, each patient is an individual.
- Be sensitive to the customs, personal space, touch, eye contacts. Do not assume that what is appropriate in the United States is appropriate in every culture. Different culture, different customs and social behaviors.
- Consider the family background and experience in deciding the appropriate care.
- Consider the traditions of the culture about the elderly. How does the culture consider the elderly and memory loss?
- Family culture will determine the choices made for the care. For examples: feeding tubes, life support, autopsies, is it appropriate within that culture?
- Consider the family's faith and spiritual beliefs. This is important in any culture.

Each culture has a different way of approaching dementia and Alzheimer's disease. The following are some examples of the difference in beliefs about Dementia and Alzheimer's disease.

- Black/African American
  - a. They attribute the symptoms of dementia to normal aging
  - b. They use prayer as a coping mechanism
  - c. They tend not to participate in studies on dementia care

- Hispanic/Latino Culture
  - a. Dementia is viewed as normal aging
  - b. Might be a punishment for past sins, caregivers must bear the cross
  - c. No services sought because it brings shame to the family
  - d. Dementia can be attributed to the “evil eye” or “nerves”
  
- Asian/Pacific Islander Culture
  - a. This group includes Chinese, Japanese, Vietnamese, Koreans, Filipinos, Cambodians, Samoans, Hawaiians, and other Pacific Islanders
  - b. Vietnamese elderly are shy and do not display physical affection; do not assume that physical contact is acceptable
  - c. Vietnamese culture is a male-centered culture
  - d. Speak softly to the Vietnamese elderly person, not staring, make eye contact
  - e. Adult Vietnamese have to begin activities including meals
  
- Native American Culture
  - a. Low Dementia occurrence in Native American
  - b. Dementia is viewed as part of normal aging
  - c. This is an “old timers’ disease”
  - d. In American Indian Culture, there appears to be no shame to Alzheimer’s and dementia

**As a caregiver you need to:**

- Be aware of personal biases, prejudices, and stereotypes.
- Value the different cultures and be aware of their differences.
- Try to get information about the patient’s culture.
- Make sure you adapt the care to fit the cultural preferences and demands. Remember that diversity is not only ethno-cultural but also geographical and includes different sexual orientation



## H. Person Directed Environments

### Choice

Choice is perhaps the most powerful word and the most abused word used in the disabilities services system. Choice equals three related concepts within this one powerful word: preferences, opportunities, and control.

- Preferences include not only what someone likes but also their desires and dreams. Preferences include: who people want to spend time with; what to do during that time; and where to spend their time.
- Opportunities are the available array of: people to spend time with; things to do during that time; and place to spend that time. Opportunities should also include being able to spend time by yourself. Preferences reflect what people want while opportunities reflect what is available.
- Control is the authority to make use of an opportunity to satisfy a preference.

(Source: Revisiting Choice – Part 1 By Michael W Smull, AAMR's News and Notes.)

### Opportunity for Personal Growth, Development and Contribution

- Residents are experts regarding life in their home. They participate in deciding about
  - The rhythm of their day
  - The services provided to them
  - The issues that are important to them in their home
- A person-centered long-term care community is a place where
  - Residents want to live
  - Personnel want to work
  - Both choose to stay

"No man can stay alive when nobody is waiting for him. Everyone who returns from a long and difficult trip is looking for someone waiting for him...Everyone wants to tell his story and share his moments of pain and exhilaration with... someone waiting for him to come back... A man can keep his sanity and stay alive as long as there is at least one person who is waiting for him". (Henri Nouwen, *The Wounded Healer*, 1979)

- Residents are given the opportunity to "contribute" to their new community.
  - Attend local church services
  - Eat at local restaurants
  - Attend community events
  - Residents not longer are titled "residents" but are horticulturists, chefs, Cuisinart specialist, cutlery specialists, or artists

Individuals needing services do not end having personal goals because they need assistance. Personal goals can be met through learning and developing or simply supporting the resident's desires for how to spend their day. Activities are those things people do during the day to remain active and engaged. They create meaning and purpose in life of each resident.

### **Activities in a Person Directed Care Environment**

- Embrace the individuality of each person by offering diverse programming that tries to meet the individual needs of each person with dementia (PWD).
- In addition to structured activities 7 days a week, opportunities exist 24 hours a day for activities that are unstructured, spontaneous, and self-scheduled.

Examples:

- A person accustomed to working nights enjoys late night movies, a snack, the radio, a good book or a time to surf the Internet.
- Residents decide to make holiday cookies and together join in this activity.
- The availability of jigsaw puzzles, crossword puzzles, or other activities encourage individuals to participate alone or with others in a spontaneous manner.
- Persons have the opportunity to access information or activities around
  - Political issues,
  - Civic issues,
  - Active engagement in national and local issues affecting their interest,
  - Voting in all elections in which they are eligible to vote.

**Staff are a creative resource rather than entertainers.**

Source: Mary Tellis-Nayak, RN, MSN, MPH. *Person Centered Long-Term Care Communities: The Future of Quality Long-Term Care*. CARF.

### **Environment**

- Take control of the furniture, don't let the furniture control you.
- Dining area that is similar to a household is preferable to long tables.
- Furniture groupings should be placed at right angles in small conversation settings.
- The environment should be created for the individuals rather than the staff. Things should be accessible and available to the individuals.

## I. Caring for Caregivers

As a caregiver, take steps to safeguard your own health and well-being. This applies to the staff that provides care as well as to the family member or friend who provides care. It is important that you attend to your own health. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.

- Do not neglect your own health needs.
- Care for yourself as passionately as you nurture the people in your life.
- Watch out for signs of depression, and don't delay in getting professional help when you need it.

As a caregiver, you should make the following part of your routine:

- Go to your primary care physician for regular check-up
- Get flu shot and pneumonia vaccine. (Supplies of the flu vaccine often run short, so be sure to obtain one early in the flu season; late fall and early winter are ideal.)
- Take medications and monitor your own health with the diligence and attention you give to those you care for.
- Be sure to take time for regular exercise. Even a short walk daily can help you maintain your physical condition, reduce your risk for certain diseases and provide psychological benefit.
- Eat a sensible, healthy diet that includes fruits and vegetables.
- Consider taking classes and engaging in stress-reduction and coping techniques. Some people find yoga, meditation and other relaxation techniques particularly helpful.
- Continue to participate in religious or spiritual activities, as well as recreational activities, sports, hobbies or simply spending time with friends.

## J. Stress Management

### Facts about stress:

- Stress is a necessary part of life.
- Stress puts us on alert and often improves our response time and results.
- Too much stress stifles creativity and efficiency.
- Care giving is a highly stressful job.

### Elements of stress:

- **Stressors** - Something that puts us on alert; it may be at home, work, self-beliefs or expectations
- **Stress Reactions**- Physical and emotional responses to stress
- **Stress mediators** – Ways of managing that prevent us from experiencing a stress reaction

### Potential Physical Effects of Stress

When a person is under stress, the body releases the primary stress hormone called cortisol. Cortisol is very important, because it organizes systems throughout the body (including the heart, lungs, and immune system) to manage the stressful event.

When a stressor continues for a long time, it can take a serious toll on the body's ability to function and may lead to many health problems. Since caregiving can be a long-term stressor, caregivers can be at risk for conditions such as:

- High blood pressure
- Heart problems
- Increased susceptibility to colds and flu

### Potential Psychological Effects of Stress

When left untreated, chronic or long-term stress can cause problems such as depression, anxiety, anger, and irritability. Some people feel that they do not have the energy to do routine tasks and wish they were somewhere else. Some people start to feel hopeless and helpless, cry often, and notice changes in their appetite or sleep patterns. They may feel exhausted and empty. In summary, stress can take away from quality of life, by lowering a person's ability to experience pleasure and a sense of accomplishment.

### **Potential Social Effects of Stress**

Caregiving can create additional stress. Caregiver's friendships and relationships often suffer due to the challenges of caregiving. Forming and maintaining social support can relieve stress by giving caregivers a chance to discuss their thoughts and feelings. It is common for caregivers to feel that no one understands what they are going through. However, caring for someone with memory problems does not have to be a lonely experience. As the behaviors and care needs change in the person with dementia, let friends and family members know when you need help, or maybe just a break. Caring for a loved one with dementia is too big a job for one person. There are many local support groups that can give you a chance to meet others who have similar experiences. You might say that you don't have time for these kinds of things, but it is important for your health and well-being that you make time. Caregiver stress can lead to illness or burnout if you do not take steps to prevent it.



## **K. Practical Strategies to Reduce Caregiver Stress & Enhance Well-being**

David W. Coon, PhD  
Department of Social & Behavioral Sciences  
Arizona State University at the West Campus  
March 20, 2006

### **STEPS YOU CAN TAKE:**

**Give yourself permission to take breaks, even for just 15 minutes at a time. Taking care of yourself helps reduce stress and keeps you healthier.**

- Take a walk or make time for other physical exercise and healthy physical outlets.
- Make time to spend with friends and family you enjoy.
- Call friends, neighbors or family on the phone to stay in touch with others.
- It's still important to laugh! Remember and use your sense of humor. Listen to tapes, records, television or people that help you laugh.
- Talk things out with a friend or get professional counseling if needed.
- Learn and practice relaxation techniques.
- Maintain religious or spiritual practices that are important to you (e.g., attend Church or Synagogue, pray, read religious literature).

**Try to solve problems as they come up rather than avoiding them. Ask for help or let others help you.**

- Establish priorities and organize time more effectively. Let the small stuff go. Again, ask for help or let others help you.
- Stop running negative thoughts and attitudes through your mind and learn healthier ways of thinking about yourself and your situation.

**Take time for your physical health.**

- Keep your own doctor, dentist, and other professional healthcare appointments.
- Take prescribed medications as suggested by your health care professional.
- Try to get enough sleep and rest. Talk with your healthcare professional and other caregivers about ways to get enough rest.
- Avoid smoking or relying on alcohol or drugs to feel better.

## **Stressssssss**

Humor is a wonderful stress reliever. Acting zany, “dark” humor (usually humor specific to a profession such as medical humor, or funeral humor) can help relieve work related a stress. Be careful. Humor must be used appropriate and never at the expense of other team members, families, or PWD.

### **Hang a spoon on your nose!**

Doing something out of the ordinary often relieves stress or helps us to place situations on a reasonable perspective. The unexpected may break the tension.

### **Summary**

- Yes... dementia caregiving is stressful
- Yes... getting rid of stress helps you, helps the team, and helps PWD
- Yes .... PWD pick up the stress within the environment; reduce your stress and you will reduce the stress of your PWD
- Yes... minimizing stress promotes dignity and respect in a dementia care setting by improving the living environment

**List one thing you will do on a regular basis to reduce stress.**

### **Good Books:**

Richard D. Carson. *Taming Your Gremlin: A Guide to Enjoying Yourself*. 1983, reprinted 1990.

Shakti Gawain. *Creative Visualization*. New World Library, 2003.



**L. Working Effectively with Your Colleagues:**

**Building a strong relationship between you and your supervisor**

DOs	DON'Ts
(1) See your supervisor as a colleague and a resource.	(1) Don't see your supervisor merely as "the boss."
(2) Ask for the information you need.	(2) Don't be reluctant or shy in seeking important information.
(3) Communicate information about changes in a resident's condition.	(3) Don't stop offering input about residents, even if you feel unheard.
(4) Keep your sense of humor.	(4) Don't react to others' anger, irritability, or other stress-caused behavior.
(5) Accept constructive criticism.	(5) Don't take criticism of your work personally.
(6) Be flexible in accepting assignments.	(6) Don't insist on certain assignments.
(7) Ask questions if you are unsure what's expected of you.	(7) Don't pretend to understand what you are unsure of.

## M. Working with Families

The purpose of this section is to discuss the realities of working with the families and friends of the person with dementia (PWD) and to determine methods for assisting families cope.

Watching someone progress through the stages of AD or other dementia is very stressful. There may be guilt associated with the inability to “do more to help the person.”

- Family members adjust to PWD in unique individual ways.
- The process of adjustment involves grief and loss, also known as **anticipatory grief** (grieving before the death actually occurs).
- Alzheimer’s disease can be a long lingering death and the stages of grief are similar to the stages of adjustment to death described by Dr. Elizabeth Kubler-Ross in her 1969 book *Death and Dying*. This adjustment process does not always occur in clearly defined stages and is influenced by the following:
  - ✓ Age and health of person with memory loss.
  - ✓ Length of illness.
  - ✓ Family relationships.
  - ✓ Roles of family members.
  - ✓ Who are the family members and how do they impact care?

The caregiving role varies with different members of the family. The role of a spouse is different from that of a grandchild. The feelings experienced by a daughter or son are different from those of a spouse. Make a list of relationships and discuss how the person’s role and relationship to the PWD may differ. For example:

- Spouse
- Adult Child – Note daughters and sons, and in-law roles are unique
- Long Distance Caregiver
- Grandchild
- Extended Family
- Friends

## N. Stages of Family Experience

(Adapted from Howard Gruetzner, *Alzheimer's: The Complete Guide for Families and Loved Ones*, chapter 8.)

**Denial** – Reflects the initial response that nothing is wrong

- Denial is a natural reaction
- Can prevent a family from seeking help
- Can create family conflict

Helpful Interventions:

- Provide accurate information on dementia when appropriate
- Listening without judging
- Do not assume person is in denial. It may be lack of information

**Over involvement** – The primary caregiver may try to meet all the needs of the person with memory loss and refuse help from everyone

- Caregiver believes they are helping
- Can create a barrier to getting help

Helpful Interventions:

- Involve family member in care and care planning
- Encourage family member to express painful feelings such as guilt, loss and anger

**Anger** – A result of the physical, emotional, financial and social burden of providing care

- Can stem from feelings of loss and abandonment
- Angry feelings can cause guilt

Helpful Interventions:

- Discuss anger at the *disease* rather than person
- Encourage interaction with other families going through disease
- Listen without judging or taking sides
- Encourage caregiver to take some time for his/her self

**Guilt**- is a feeling that comes from a sense of wrongdoing in words, actions or thoughts. Guilt can come from:

- Old conflicts
- Wish for the patient to die
- Placement and other tough decisions
- Feeling like you “have not done enough”

Helpful Interventions:

- Learn about guilt and how it affects residents' families
- Encourage caregiver to talk about guilty feelings if appropriate

**Acceptance:** This is possible when the process of the disease and its effect on others is fully understood. Remember: families can still revert to earlier stages of adjustment

Helpful Interventions:

- Enable caregiver to see setbacks as temporary
- Encourage caregiver to pursue personal interests and hobbies
- Encourage involvement in care, (if appropriate) and continue to ask their help/support on issues of caregiving

## Acceptance

You have Alzheimer's disease  
and you're losing the power  
to remember-to reason-to understand,  
to do the simple tasks  
we take for granted:  
to put on a shoe-  
to button a shirt-  
to read a book-to remember a face or name.

It's a hard thing to understand-  
to accept.....  
Perhaps it's been hardest for me,  
for I've lived with you-  
but I know-you can't help it-  
can't act otherwise...

I must take you as you are  
And expect-not more-but less  
as the disease continues to progress.

Maude S. Newton, Caregiver

Source: Alzheimer's The Complete Guide for Families and Loved Ones by Howard Gruetzner (p. 106.)  
Permission to reprint copyrighted material granted from John Wiley & Sons, Inc. publishers, Hoboken,  
NJ. August 2002.

## O. Coping Strategies for Families and Caregivers

- Learn about AD to understand what is happening to the person with dementia (PWD).
- Develop realistic expectations about the future.
- Accept past mistakes; learn from them and go on.
- Become aware of your mental and physical reactions to stress.
- Accept and enjoy your successes and breakthroughs, but accept that they are temporary.
- Accept your own feelings of frustration or anger at the person with AD.
- Realize that taking out these feelings on the person with AD is NOT acceptable.
- Take care of yourself.

Families feel particularly helpless and guilt-ridden when they turn over the care of a loved one to others in a directed care setting. Of course, part of them knows that this is best for the person with AD, but another part believes that they should have done more.

When a PWD is placed in a directed care setting, both the resident and family struggle to develop new roles and adapt to new settings

- Concern about being a parent to their parent
- Concerns about the community condemning their decision to place their family member
- Concerns about the care received
- Grieving for lost ability
- Concern about the future

Sometimes family members may be worried that they will also get AD. This is a legitimate concern as AD does occur more often in members of the same family. Other risk factors are:

- Over 60
- Female
- Previous head injury

**Caregivers can help families adjust to the changed circumstances:**

### **Be Yourself**

- Remember that you took this job to help people!
- Approach family members in a friendly and relaxed way.
- Don't tell them you are overworked or too busy.
- Listen to the family's method of providing care – you may learn some new tricks!
- Share problems (and successes) you are having with their loved one (within reason) and ask their advice.

### **Be a Good Listener**

- Pay attention to what they say and what they do.
- Repeat what they say back and ask them to clarify it.
- Ask questions and listen to answers.
- Don't take complaints personally!

### **Understand the Family is Grieving**

Their anger, frustration, helplessness, complaints, suspiciousness, condescension and unrealistic expectations are part of the grieving process.

### **So, What Can I Do?**

- Empathize – “It’s very understandable to be upset in this situation.”
- Let them help with care & offer suggestions.
- Encourage them to attend a support group.
- Talk about their loved one as if a part of your family.
- Take their advice occasionally and tell them what happened.
- Use the family as a “consultant.”
- Always approach them first (with a smile).
- Ignore a condescending approach; it simply means they are angry at their situation (the demeaning illness).
- Don't take it personally.
- Talk with your social worker, pastoral counselor or D.O.N. about a family's concerns and the effects on you.

### **Let the Family Know How Special Their Loved One Is To You**

- Ask the family to tell you about the person before the illness.
- Talk with the family about the good times.
- Develop a committee to plan family staff activities, such as potluck dinners.
- Write notes to the family.
- Remember a spouse's birthday and anniversary with a card.
- If the family brings a gift, write a thank you note.
- When the resident passes on, send a sympathy card.

**Understand that you are a *special person* in the lives of this family.**

## **P. Case Studies**

Discuss the following cases and suggest two or three ideas from the practical tips you discussed to help the family members.

- Be sure to note when the caregiver can manage the situation, and when he or she needs to get a supervisor involved.
- Discuss several approaches to resolving the issues – there's more than one right answer.

### **Scenario #1 "The Demanding Daughter from California"**

The 48-year-old daughter, "Jolene," travels from California to visit her mother, "Margaret," in the directed care center twice a year. On each occasion, Jolene is full of criticism about the care. She spends hours at the care center crying and fretting over her mother, who is in the late-middle stages of AD and doesn't recognize her daughter at all. At every opportunity, the daughter approaches the staff with, "why don't you do this or that differently?" All of this is upsetting to Margaret, who becomes more agitated during her daughter's visits. The daughter wants to know what **you** are doing that is upsetting her mother.

### **Scenario #2 The Manipulative Family**

This large family makes frequent visits to the care center to see their father and grandfather, "Harry," who recognizes his own sons and daughters, but gets confused about the identity of the grandchildren. Family members visit in groups of 3 or 4. On this visit, they approach you with stories about another caregiver in the center. The stories suggest that another caregiver has not been as careful with Harry as they would have liked. They compliment you on the care you provide, and ask, "Since you do better with him, can you be assigned to take care of him everyday?"

### **Scenario # 3 - The Angry Family**

“Thelma” is in the late stages of AD, and her husband, “Ted” visits her on two or three times a week. As the changes of late stage AD become more evident, Thelma’s son and daughter have gotten more and more concerned about their mother. They demand that you spend more time with their mother, because clearly the care is not as good as it once was, or she would be doing better. You overhear a conversation in which the son is advising his father to hire a lawyer “who will make these people do what’s right.”

### **Scenario # 4 The Family that Stays and Stays**

“George” was recently admitted to the center in late middle stages of AD. “Margaret,” his wife, arrives early in the morning and stays until late at night every day. She is very attentive to her husband, who recognizes her and begs her to stay with him. She insists that she should feed him all his meals and she brings only a sandwich and an apple for herself. Margaret helps with the bathing and dresses George and sits with him outside in good weather. George has shown no interest in participating in activities.

**Remember . . . You and the Family Want the Same Thing:  
Good care for the person with dementia!**

**Build on each other’s strengths, because you’re on the same team!**



**SECTION II QUESTIONS**

1. The Alzheimer’s Disease Bill of rights include the right:
  - a. To be treated like an adult, not a child
  - b. To be outdoors on a regular basis
  - c. To have physical contact, including hugging, caressing, and hand holding
  - d. All of the above
  
2. The people with the best knowledge about dementia are the doctors and the brain scientists according to the New Dementia Culture
  - a. True
  - b. False
  
3. List and explain 5 characteristics of the New Dementia Culture

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4. A settled, patterned way of giving meaning to human existence in the world and giving structure within it is a definition of:
  - a. Dementia
  - a. Personhood
  - b. Reality
  - c. Culture
  
5. Cooperation and collaboration instead of competition and conflict is:
  - a. One of the new cultural norms
  - b. How we maintain personhood
  - c. The opposite of what to do
  - d. All of the above
  
6. An insightful awareness to share the emotions, thoughts, and circumstances of another person is a definition of:
  - a. Psychic energy
  - b. Compassion
  - c. Respect
  - d. Empathy

7. Maintaining and Enhancing of Personhood include:
  - a. Empathy and Compassion
  - b. Individuality and Autonomy
  - c. Independence
  - d. A and B
  
8. Cultural diversity needs to be carefully considered by the caregiver in Dementia care and includes consideration of the patients' customs, family background and culture
  - a. True
  - b. False
  
9. Black/African American and Native American cultures both consider dementia as part of normal aging.
  - a. True
  - b. False

## SECTION III - COMMUNICATING WITH THE PERSON WITH DEMENTIA

### Techniques for Successful Verbal Communication

- Introduce yourself by name/association
- Validate responses and feeling verbally
- Use short simple sentences
- Ask primarily yes/no questions
- Allow time for a response
- Use word cues - try to guess what the person wants

This session is designed to provide guidelines for communicating with the person with AD. This session expands on the culture of care and suggests practical applications for handling communication by using the “soft approach” and redirecting the PWD to produce a more positive interaction.

#### **In communicating with residents, you will want to:**

- Introduce yourself by name/association.
- Validate responses and feelings verbally.
- Use short simple sentences.
- Ask primarily yes/no questions.
- Allow time for response.
- Use word cues - try to guess what the person wants.

Redirect the person to produce a more positive interaction.  
(See the *Communication Techniques* Handout)

#### **Six qualities to use when communicating with Person with Dementia (PWD):**

- P** – positivity
- E** – empathy
- R** – respect
- S** – sincerity
- O** – openness
- N** – nonjudgmental attitude



**Implement these techniques when communicating with a PWD:**

- Use a simple verbal approach with concrete and familiar words
- Prompt instead of testing the PWD's knowledge
- Use non-verbal cues to help the PWD understand
- Use a calm, pleasant tone
- Avoid use of judgment and maintain a strong sense of respect for the PWD
- Provide validations of the PWD's experiences and feelings
- Redirect and distract out of stressful situations
- Use patience and repeat yourself as needed

## A. Techniques for Verbal & Non-Verbal Communication

### SUCCESSFUL VERBAL TECHNIQUES

In the early and for part of the middle stages, verbal techniques may be used to calm and reassure the person with dementia (PWD). You can redirect the person to achieve a more positive interaction.

Discuss the following example: The PWD says, "Papa is coming to get me." If you said, "No, Papa died years ago," the PWD would either begin to grieve for him or refuse to believe what you are saying. Instead try something like, "You must miss him. What kind of work did he do?" or "What things did you enjoy doing together?"

These statements allow the PWD to respond to the idea of the lost person and go with the flow of his/her ideas. Direct the PWD to think about positive memories of the person, rather than the idea that Papa is no longer alive.

### SUCCESSFUL NON-VERBAL TECHNIQUES

#### Techniques for Successful Non-Verbal Communication

- Approach gently from the front
- Establish eye contact on the same level
- Reduce or eliminate background noise
- Use items to provide visual cues
- Nod head for agreement and encouragement
- Smile
- Touch gently
- Wave goodbye

In the **soft approach**, actions speak louder than words:

- Smile and approach gently from the front.
- Establish eye contact on the same level.
- Reduce or eliminate background noise.
- Use items that provide visual cues.
- Nod the head for agreement or encouragement.
- Smile.

- The goal is to avoid ANY situations likely to create anxiety or conflict. Both cause distress in the PWD.
  - WATCH how the person responds to the non-verbal messages you are sending.



Successful non-verbal techniques are used in conjunction with words to reinforce messages of safety, comfort and security. Caring non-verbal messages are helpful at all stages of the disease.

**Examples:**

Gentle touching to put the person at ease. Try touching the cheek, back of the neck, shoulders, and upper arm when the person is not aggressive. Hum or softly sing well-remembered songs.

For greatest effectiveness, the verbal and non-verbal messages must be in agreement with each other in tone. A PWD is very sensitive to tone, voice, and body language.

## **B. Skill Building – Verbal & Non-verbal Communication Techniques**

The following two scenarios present situations that will allow you to practice communication techniques.

### **Case Scenario One: Margaret at Bedtime**

Laurie was assigned to assist Margaret with getting ready for bed. Margaret was accustomed to getting her nightgown on by herself and was very shy about being undressed. Laurie knocked on the door and entered Margaret's room to assist her. She found Margaret had put her nightgown on over her clothes.

Laurie didn't think that Margaret would be comfortable sleeping in her clothes, so she wanted to convince Margaret to take off the nightgown. Margaret resisted and Laurie began using a hands-on approach to help her.

Since Margaret's ability to communicate is moderately impaired and she was unable to express her fears and frustration, she became increasingly agitated. She tried to tell Laurie that she was shy and embarrassed, but could not verbalize her feelings and instead pushed Laurie away and threw the nightgown on the floor...

What would you do to help Margaret cope with her escalating behavior, help restore her dignity, and provide assistance in getting ready for bed?

1. Discuss this scenario and determine which communication techniques apply.
  
  
  
  
  
  
  
  
  
  
2. Practice: You will be practicing the skills used to communicate with the person with AD by acting out this scenario to a successful conclusion.
  - One person will act as Margaret.
  - One person will act as Laurie.
  - The remainder of the groups will watch the scenario and offer observations about the communication skills used by Laurie.

## Case Scenario II: Frank has Visitors After Dinner

Later that same week, Laurie is caring for Frank and is building a trusting relationship with him. Trust and a friendly approach are very important to Frank, since he can become agitated quite easily. Even though Laurie heard from other caregivers that Frank verbalized unusual stories, Laurie has not experienced that type of communication with Frank.

Laurie and Frank have been getting along very well until one evening just after dinner. Shortly after entering his room, he comes out of his room calling out for "Help!" Laurie comes running and asks Frank, "What happened, Frank, are you all right?" Frank is very distressed and tells Laurie there were four people in his room, each one yelling and screaming at him to "Get out, get out!" Laurie wants to reassure and comfort Frank.

What communication approach will you use to convince Frank that it was safe for him to go back into his room and get some sleep?

1. As a group, determine which communication techniques to use in case scenario II.
2. Conduct a skill practice that reinforces the verbal and non-verbal skills that will help resolve this situation.
  - One person will act as Frank.
  - One person will act as Laurie.
  - The remainder of the groups will watch the scenario and offer observations about the communication skills used by Laurie.

**When you are done, review the "Alzheimer's Bill of Rights" on page 24.**



## C. Communicating with Peers for More Effective Dementia Care

### Tips for Communicating Effective Messages to Co-Workers

- Maintain good eye contact
- Speak clearly and directly
- Use the person's name whenever possible
- Use a friendly tone of voice
- Ask for repetition or clarification if you are unclear about a message
- Never yell or discuss resident's care in front of that resident or other residents
- Carefully report critical information related to a resident's achievements and challenges related to health, behaviors and ADL care for consistency
- Take notes when appropriate to assist in improving communication and note in residents' charts

### Apply Tips for Communicating Critical Information to Co-Workers

1. Clearly state to co-workers what residents had achieved during the previous shift.  
**Example:** "With very little prompting, John came out of his room for the first time to participate in softball today."
2. Use specific behaviors to describe any physical changes you have observed.  
**Example:** "Mary appears to take long to move from her chair to the dinner table. I'm concerned about this change and believe we need to watch her closely."
3. When you are unclear about what a co-worker has said regarding a resident that you will be responsible for, be assertive and ask for the information to be restated.  
**Example:** Lisa was looking down at the floor and mumbling when she was reporting on some of the residents. Angie was the next person to be responsible for the same residents but she hadn't heard much of what Lisa said. Angie was assertive and confronted Lisa by saying, "Would you please say that again, I couldn't understand you."

4. When your supervisor has just completed a care plan session and has given several instructions with timelines, it is your responsibility to receive the information accurately. Summarize the instructions, if necessary.

**Example:** "Mrs. Nelson, I understand you want all of our residents ready for an outing by 10:00 a.m. with their name tags on and a jacket in case it gets cold."

### **Discuss Successful Aspects of Teamwork among Caregivers**

1. Open communication among co-workers
2. Support from co-workers when you least expect it
3. Pitching in when others are not available
4. Having mutual respect for your co-workers
5. Being a good listener and relaying appropriate information
6. Giving praise and positive feedback to others

### **D. Concept for Building a Strong Caregiver T.E.A.M.**

- T** Trusting yourself and others.  
Trusting builds a sense of acceptance of others.  
Trusting creates confidence in self and others.  
Trusting establishes a "safe harbor" and feelings of security.
- E** Empowering yourself to be your best.  
Empowering gives permission of excel.  
Empowering challenges your ability to be creative and innovative.  
Empowering authorizes you to explore your talent and uniqueness.
- A** Attitude can be your best friend!  
Attitude creates positive and negative reactions (you decide!)  
"Can do" attitude contributes to the well being of others.  
Attitude reflects your true character.
- M** Modeling teamwork to others.  
Modeling good teamwork is an example for others.  
Modeling exhibits a sense of cooperation.  
Modeling encourages others to be "team minded"

### SECTION III QUESTIONS

1. The first letter of the six qualities to use when communication with a person with dementia spells the word:
  - a. Person
  - b. Patient
  - c. People
  - d. None of the above
  
2. Important verbal communication techniques include the following:
  - a. Introducing yourself by name/association
  - b. Allowing time for a response
  - c. Avoid yes/no questions
  - d. A and B
  - e. B and C
  
3. Which of the following is not true about the soft approach?
  - a. Smile and approach gently from the front.
  - b. Do not establish eye contact.
  - c. Nod the head for agreement or encouragement.
  - d. Reduce or eliminate background noise.
  
4. Which of the following is not an effective technique for communicating with co-workers?
  - a. Maintain good eye contact.
  - b. Speak clearly and directly.
  - c. Avoid repeating or asking questions about a message.
  - d. Take notes when appropriate.



## **SECTION IV - DEALING WITH DEMENTIA RELATED BEHAVIORS**

This section defines “problem” behavior commonly seen in the PWD and provides helpful methods for assessing, preventing and dealing with difficult situations.

### **Objectives:**

1. Discuss the basic strategies used to identify, avoid and deal with behavior problems of the PWD.
2. Demonstrate the “soft approach” in working with a PWD.
3. Discuss your critical role in providing functional ability in the daily routine.
4. Describe methods to manage the risks to the PWD when performing activities.
5. Identify the methods that enhance dignity and respect for the PWD.

### **COMMON BEHAVIORS**

- Resisting/fighting hands-on caregivers
- Assaultive toward peers
- Wandering and rummaging
- Physical restlessness
- “Sundowning”
- Eating problems
- Sleep disturbances
- Disruptive yelling or moaning
- Problematic sexual behavior
- Disrobing

## A. WHY BEHAVIORS OCCUR:

### 1. Brain Changes:

- Effects on the Brain. AD involves areas of the brain that control emotions and behavior.
- The Brain and Behavior. As a result, many PWD exhibit increased volatility, and are more prone to have behavior problems associated with aggressive and acting out behaviors.

### 2. Confusion:

- Confusion. The profound confusion caused by dementia makes it difficult for PWD to understand their surroundings and what is going on around them
- Emotional/Behavioral Responses. When people are confused they are more likely to feel anxious, afraid, suspicious, and/or angry, and they are much more likely to act out and exhibit problem behaviors

### 3. The Nature of Caregiving:

- Need for Care. PWD have increasingly greater needs for hands-on care.
- Caregiving is Intrusive/Uncomfortable. Caregiving involves highly personal, intimate, and intrusive actions on the part of caregivers. These actions can be physically and emotionally uncomfortable and distressing to PWD.
- Emotional/Behavioral Responses. The intrusiveness and physical nature of caregiving often triggers reflexive emotional and behavioral responses from PWD, including resisting/fighting, yelling/crying, and other symptoms of emotional distress.
- The Impact of Caregiver Approach on Behavior. The actions and reactions of caregivers are two of the most important factors in determining whether or not AD residents exhibit behavior problems. Caregivers can trigger problems and make them worse, or they can minimize them and make them better.

### 4. Pain:

- Incidence. PWD have a high incidence rate of untreated pain.
- Communication Deficits. PWD often cannot accurately indicate, describe, or otherwise verbalize their pain. They often express their pain indirectly through their emotions and behaviors.
- Behaviors Resulting from Pain. Many of the common behaviors exhibited by PWD (e.g., resisting/fighting care, not eating, yelling, crying, restlessness, disturbed sleep) are actually very basic and reflexive responses to pain.

**5. Acute Medical Problems; Delirium:**

- Susceptibility to Illness. PWD may be medically fragile and easily contract infections and other acute medical conditions.
- Adverse Medication Reactions. PWD may exhibit an increasing vulnerability to adverse reactions from medications.
- Delirium. PWD have an increased likelihood of delirium whenever they become ill, or whenever they suffer adverse reactions to medications.
- Distinguishing Delirium from Dementia. Because of their impaired cognition, it can be difficult to distinguish delirium from dementia in PWD. As a result, underlying acute medical disorders may go undiagnosed.
- Sudden Behavior Changes. Sudden changes in behavior are often indicative of delirium. In most PWD, delirium causes an exacerbation of cognitive, behavioral, and functional problems.
- Behavioral Indicators. Behaviors associated with delirium may include agitation, akathisia, extreme lethargy, crying/moaning, repetitive vocalizations (including yelling), changes in appetite, and/or changes in sleep pattern.
- Psychosis. Psychotic symptoms, such as hallucinations, delusional thinking, paranoia, and bizarre behaviors, are often symptomatic of delirium. In cases where there is a sudden onset of psychotic symptoms, caregivers should immediately arrange for a medical evaluation to assess for acute medical problems that could be causing the psychosis.

**6. Environmental Stressors:**

- Behaviors Reflect the Environment. The behaviors of PWD often reflect obvious or subtle characteristics of the environment.
- Sensory Stimulation. If the environment is either over-stimulating or under-stimulating, or if it has a negative, disturbing, or institutional/sterile quality to it, PWD may behave in a distressed or agitated fashion. PWD require a balance of sensory-enhancement and sensory-calming activities within their environment.
- Unfamiliar Settings/Transitions. PWD often exhibit distress when in unfamiliar settings and may show increased behaviors. As a result, moving to a new living situation often results in new or exacerbated behaviors.

## B. The *Dementia Care Philosophy* as it Applies to Behavior.

Always apply the Dementia Care Philosophy when working with Behaviors.

- **Respect, compassion, and dignity** must be maintained at all times.
- **Individuality.** Every PWD is a *unique individual*, and must be treated that way.
- Caregivers should strive to develop close **personal relationships** with PWD. Knowing the PWD helps in understanding that person and in anticipating his/her needs.
- Using a sound Dementia Care Philosophy greatly diminishes problems behaviors.
- **The attitude and approach of the caregiver are critical.** Use a “soft,” gentle, comforting approach at all times.

## C. Key Principles

1. **Don’t intervene** unless one of the following applies:
  - The behavior significantly violates the rights of others.
  - The behavior poses a significant threat to someone’s safety or health.
  - The behavior makes it significantly difficult to meet government regulations.
2. When it IS necessary to intervene, keep in mind these **priorities**:
  - **Safety:** The first priority is insuring that PWD are SAFE.
  - **Comfort:** Maximize comfort at all times and in all ways. When PWD are comfortable, they are less likely to exhibit behavior problems.
  - **Behavior as Communication:** PWD communicate through their behavior. With this in mind, caregivers should assume that behavior problems represent a message in which the PWD is telling the caregiver that something is wrong and needs fixing.
  - **Clarity.** When residents truly understand what is going on, they are less likely to be confused or afraid. A goal is to make the environment, especially caregiving situations, as clear as possible.
  - **Unmet needs:** When their needs are not being met, PWD often exhibit behavior problems. Caregivers should anticipate and address all needs. This is much easier to do when the caregiver comes to know the PWD very well.
  - **“Soft Approach”:** Use a soft voice, soft actions, soft expressions, and soft touch. Smile and maintain a warm demeanor. Go slow. Talk using short, simple, concrete words/sentences. Go one-step-at-a-time. Always be gentle, kind, apologetic, and respectful. Never correct or confront. When PWD get upset, back off, re-establish rapport, engage/distract, then re-approach. Or simply leave and come back later.



## D. Prevention

1. **Good Care:** Preventing behavior problems starts with good care. The knowledge, skills, techniques, and approaches of caregivers are all critical factors in the cause and treatment of behavior problems.
  
2. **Focus on Comfort:** Dementia care is comfort care. Caregivers should always strive to make PWD as physically and emotionally comfortable as possible. The goal of caring for PWD at all levels is to maximize their comfort. Comfort is a multifaceted concept that includes the physical, sensory, emotional, environmental, social, and spiritual well-being of the individual.
  - The sense of confusion experienced by PWD makes them far more susceptible to physical and emotional discomfort.
  - It may be challenging to assess and effectively enhance the comfort levels of PWD since their communication skills are diminished by their dementia (e.g., they may not be able to say that they are in pain).
  - PWD who are truly comfortable exhibit far fewer behavior problems.
    - Comfortable people don't hit
    - Comfortable people don't yell or scream
    - Comfortable people don't moan or cry
    - Comfortable people don't act agitated or distressed
  - Maximum comfort is achieved through good caregiving. PWD who are well cared for exhibit far fewer behavior problems than those who are not well cared for.
  - The "soft" approach is designed to maximize comfort during care situations and all interpersonal interactions/relations.
  
3. **Anticipate Needs:**
  - Caregivers should be proactive in addressing the needs of PWD by anticipating those needs ahead of time, especially since PWD often require a great deal of care and may not be able to verbalize their needs.
  - This requires the caregiver to know the PWD extremely well, including all the subtle, highly individual nonverbal cues the PWD exhibits to communicate his/her needs.
  
4. **Environment:** Maintain a dementia-friendly environment that is safe, comfortable, and at the appropriate level of stimulation.
  
5. **Philosophy:** Maintain a philosophy of respect, dignity, compassion, and individuality at all times.

## E. INTERVENTIONS

### When Problems Do Arise: Guiding Principles

1. **Philosophy:** Maintain a philosophy of respect, dignity, compassion, and individuality at all times.
2. **Identify and address unmet needs.** Areas to consider include:
  - Illness (acute and chronic)
  - Pain of any type
  - Other physical discomforts and associated needs (e.g., hunger/thirst, hot/cold, positioning problems, bowel/bladder needs, etc.)
  - Emotional needs associated with environmental stressors, sensory stimulation, and meaningful human contact
  - Sensory deficits, such as diminished vision or hearing
3. **Assess and treat sources of pain.**
  - PWD may not be able to clearly communicate the location of their pain or even that they are experiencing pain.
  - Consider nonverbal cues such as facial expressions, behavior, motor functioning, voice tone, posture, etc., when performing a pain assessment with PWD.
  - Pain medication should be considered and tried before resorting to psychotropic medications in the treatment of behavior problems for PWD who cannot communicate well.
  - As with all medications, the side effects of pain medications should be considered, including the possibility of delirium lethargy, or acute confusional states.
4. **Watch for early warning signs** and intervene early. Before a behavior escalates, pleasantly interrupt the behavior with a positive interaction that engages the PWD and distracts his/her attention away from the problem.
5. **Knowing/Understanding the PWD.** It is critical that caregivers have a deep knowledge and understanding of the PWD for whom they provide care.
  - Learn the PWD's history. Obtain and post written life histories ("life story" or "biosketch") as a means of helping caregivers better understand who the PWD is and what makes him/her unique.
  - Knowledgeable caregivers are more likely to anticipate the needs of PWD and thus avoid behavior problems before they begin.
  - Astute caregivers are more likely to notice subtle changes in the moods and behaviors of PWD, and are better equipped to notice and resolve critical comfort issues.
  - Knowledgeable caregivers are more likely to identify and resolve early warning signs of behavior problems before they escalate.

## 6. Problem Solving.

- Never assume that a behavior is a direct symptom of the dementia and therefore cannot be resolved.
  - There is always a reason why a PWD acts the way he/she does.
  - It is the caregiver's job to investigate to the point of uncovering and resolving that reason.
- Treat problems empirically through trial-and-error. For example, sometimes we cannot know if pain is the cause of a behavior until we try routine pain medications to see how they affect the behavior.
- If solutions are not obvious, look at several different dimensions simultaneously. Systematically assess the following areas:
  - Basic comfort needs
  - Emotional needs
  - Pain
  - Illness
  - Environmental changes and stressors
  - Social stressors
  - Sensory deficits

If there is a positive response, go back and systematically review interventions to determine what was effective.

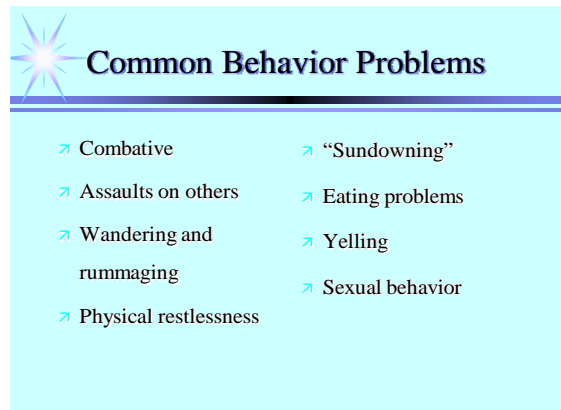
- Realize that PWD may respond more negatively to certain caregivers than others. Attempt to match-up caregivers with PWD in a manner that establishes the best relationship between the two.

## 7. Identify and change antecedents to behaviors. Identify, change, and control those antecedents that trigger the behavior. Steps include:

- Describe the behavior and determine the frequency, duration, and intensity of the behavior.
- Identify the circumstances under which the behavior occurs, including location, time of day, people involved and their actions, levels of environmental stimulation, activities occurring, etc.
- Systematically alter antecedents until the behavior improves or resolves.
- Continue to control behavioral antecedents so that only those antecedents that trigger positive behaviors are present.

8. **Caregiver Approach.** The caregiver’s response to behavior problems has an enormous impact on whether or not the behaviors will diminish or escalate. Therefore, the caregiver’s approach is a significant factor in what happens to a behavior.
- Use the “soft approach”, which is designed to help PWD feel calm, comfortable, and safe.
    - Smile; pleasant facial expressions
    - Warm, friendly demeanor
    - Soothing, pleasant voice tones
    - Gentle touch
    - Slow, calm reactions
    - Consistency in environment, routine, activities, and caregiving approaches
    - If the PWD gets upset, consider leaving him/her alone for a few minutes, giving him/her time to calm down, before re-approaching
    - Avoid arguing, correcting, confronting, or other negative interactions
    - Use prompts and cues, rather than challenging or directing
  - Engage PWD in a personally meaningful fashion that draws their attention away from the upset and distress of the situation. Examples include:
    - Offer something to eat or drink
    - Go for a walk; go outdoors
    - Talk in a calm, soothing way about any topic that seems to positively engage the PWD
    - Play music; sing a song
    - Look at pictures
    - Say a prayer; sing a hymn
    - Pleasant exercise
    - Reminiscing
9. **Engage and Distract.** When PWD have behavior problems, do not directly focus on the upset. Instead, refocus their attention onto positive topics, activities, or objects.
- Offer them something to eat; go for a walk; sing a song; talk about a pleasant topic; give them a hug. Engage them in a favored pleasant interaction that makes them feel good and lose track of the upset.
  - Never confront or correct PWD about their behaviors. Do not try to reason with them about their behaviors. Do not ask them, “What’s wrong?”, or “Why are you upset?”, or “Why did you do that?”

## F. Dealing with Common Behaviors



- **Fighting/Resisting Care:** Maintain compassionate dementia care philosophy at all times. Use the “soft” approach to avoid triggering combative responses. Back off, apologize, act “soft”, engage and distract attention away from upsets when a PWD gets upset or combative. Re-approach with the “soft” approach once the PWD calms down.
- **Assaultive towards Peers and Caregivers:** Look for people/situations that consistently trigger assaults and strive to change those triggers. Look for early warning signs and intervene before they escalate. Use the “soft” approach while engaging and distract attention away from upsets.
- **Physical Restlessness:** Allow and tolerate restlessness. Maintain a soothing, low-stimulation environment. Only consider medications if PWD are uncomfortable or are endangering themselves or others. Do caregiving “on the run”, including eating (if necessary). Allow sleep wherever/whenever they like, no matter what time of day or night if the situation allows. Use soothing music and soothing touch.
- **Poor Intake:** Focus on individual food/drink preferences. Use lots of snacks; offer frequent dementia-friendly preferred food and fluids (e.g., soft and sweet) during waking hours, unless against physician orders. Give PWD as much to eat as they want. Use finger foods and let them eat “on the run.” Fortify foods.
- **Disruptive Yelling:** Anticipate needs. Check for pain and treat any and all possible areas of discomfort (e.g., hunger, thirst, clothing, positioning, environment, etc.). Push food and fluids and good bowel/bladder care. Maximize mobility. Maintain a soothing environment. Preoccupy attention. Keep stimulation low and soothing, but don’t isolate.
- **Distressed Moaning/Crying:** Consider same guidelines as for disruptive yelling (see above). Be attentive and supportive, but do not directly focus on the upset or the behavior. Instead, engage and distract the PWD’s attention onto more pleasant conversations and activities.
- **Sleep Disturbances:** Allow PWD to sleep according to their own individual sleep patterns and schedules, including during nighttime hours (whenever the situation will allow). Avoid using tranquilizers for sleep unless absolutely necessary. Don’t try to keep PWD awake all day in order to get them to sleep at night (will cause “sundowning”).

- **Problems Sexual Behavior:** Consider that the behavior may not truly be sexual. Do not allow sexual behavior between two PWD unless both have the capacity to make and fully understand their decision/actions. If not, minimally require that all family members consent. Distract attention away from problems situations. Don't confront. Consider restrictive clothing.
- **Fall Risk:** Closely supervise and be vigilant. Make sure chairs and beds are comfortable. Consider chairs that have safety enhancing qualities (check with an OT specialist). Consider safety alarms and detectors. In virtually all cases, physical restraints should not be used.
- **"Sundowning":** "Sundowning" is often due to disturbed sleep/rest patterns (especially if forced by caregivers), uneven or ill-considered medication schedules, inconsistent eating patterns, or changing levels of environmental stimulation. Try carefully assessing and making changes in one or more of these areas.
- **Psychosis and Related Behaviors:** Learn to distinguish psychosis from confusion (e.g., confused thinking is often mislabeled as psychotic thinking). Also, some forms of dementia are more prone to psychosis (e.g., Lewy Body type dementia) than others. Sudden onsets of psychotic thinking/behavior are usually indicative of acute medical problems and associated delirium – consult a medical provider. Be supportive, but do not directly address delusional or paranoid thinking; instead, engage and distract to more pleasant reality-based activities.
- **Wandering and Rummaging:** Maintain a care setting that can tolerate wandering and rummaging and that is safe. Use environmental cues (lighting, colors) that help to better orient PWD. Pleasantly engage and distract PWD out of problem situations.
- **Disrobing:** PWD who disrobe are generally uncomfortable and are communicating some sort of unmet need (e.g., toileting). Rarely is disrobing sexual in nature. Make sure clothes are comfortable and room temperature is comfortable. Consider comfortable clothing that is not easy to remove.

## G. Medications in Treating Dementia-Related Behaviors:

The following is provided as background information. Only skilled professionals trained, qualified, and experienced in the use of psychoactive medications with PWD should prescribe psychoactive medications to PWD (e.g., geriatrics boarded psychiatrists and neurologists, geriatrically trained psychiatric nurse practitioners, board certified geriatricians). It is more challenging to effectively use psychoactive medications with older persons and dementia residents than with younger persons.

- Older persons and dementia residents are more likely to have negative side effects from psychoactive medications than younger persons.
- Dementia residents may not be able to report medication-related problems. They need caregivers to watch for problems and advocate for them.

**Guidelines for use of medications:**

Whenever a resident exhibits an acute exacerbation of confusion, agitation, or lethargy, assesses and treat for possible acute medical problems before considering psychoactive medications.

- Consider using caregiver-based behavioral or environmental approaches before considering psychoactive medications.
- Only skilled professionals trained, qualified, and experienced in the use of psychoactive medications with PWD should prescribe psychoactive medications to PWD (e.g., geriatrics boarded psychiatrists and neurologists, geriatrically trained psychiatric nurse practitioners, board certified geriatricians).
- Start low, go slow (be conservative) with psychoactive medications.
- Avoid poly-pharmacy with psychoactive drugs, whenever possible.
- With older residents, the recommended dosages for most psychoactive drugs are considerably lower than dosages for younger persons.

**What to watch for:**

- Increased confusion
- Increased agitation (many drugs have paradoxical effects)
- Over-sedation (could impact gait, appetite/intake, responsiveness, functional status, etc.)
- Any other coinciding and undesirable cognitive or behavioral effects

**What to do if problems arise:**

- Contact the physician and/or behavioral health professionals involved in the resident's care.

Least Restrictive Environment. PWD should reside in a setting that is the least restrictive possible, given their abilities, limitations, behaviors, and care needs. As a result, residential settings should be as restraint-free as possible. Assisted living settings may not use restraints of any form for any reason, per federal and state regulations. Skilled care settings are severely limited in the types and uses of restraints, per federal and state regulations, and should endeavor to be completely restraint-free whenever possible. Psychotropic medications may be considered restraints, and are governed by federal and state policies and guidelines. Use of such medications must be considered carefully and well-documented.

Moving a resident out of your facility due to behaviors. Facilities have a commitment and ethical responsibility to care for their residents and to appropriately handle all caregiving issues, including those related to behavior problems. As long as a resident is appropriately placed in a setting that fits his/her needs and level of care, the resident has a right to stay in that setting (see state regulations). Only when that setting is determined to be legitimately inadequate to care for the resident's needs — according to level-of-care standards set by the state — can the facility forcibly remove the resident to another setting (doing so using procedures mandated by the state).

### **When to get help:**

In-house caregiver efforts alone are not always effective in dealing with behavior problems. Get help from qualified behavioral health professionals whenever:

- Anyone is believed to be in danger, including peers, caregivers, or the PWD him/herself.
- If any resident's quality of life is significantly diminished due to the PWD's behavior.

### **How and where to get help:**

Contact the primary care doctor or a facility supervisor immediately, or contact one of the following resources:

- A behavioral health professional with expertise in geriatrics and dementia care (e.g., psychiatrist, psychologist, neurologist, psychiatric nurse practitioner).
- A medical practitioner with a specialty or expertise in geriatrics and dementia care, including a geriatrician or other type physician, nurse practitioner, or physician's assistant.
- The "Helpline" of the Alzheimer's Association, Desert Southwest Chapter, for possible referral alternatives.
- The "Helpline" for the Area Agency on Aging for additional resources and referrals.
- The National Council on Aging and Governor's Benefits Check-Up Program for available benefits and funding information



## H. Difficult Behavior Practice Situations:

Discuss the following situations in small groups and determine how to respond in each case. Refer to your handout on “Dealing with Behavior Problems.”

### **Situation # 1**

**Ralph**, in the late-middle stages of AD, is following you around all day, and asking you “Where will I sleep tonight?”

### **Situation # 2**

**Ruth**, a person in the middle stages of AD resists attempts to help her brush her teeth or bathe. She hits caregivers when they attempt to help her.

### **Situation # 3**

**Martha**, in the early-late stages of AD, is getting up frequently at night and resists your efforts to help her back to bed.

### **Situation # 4**

**John**, in the middle stages of AD, is wandering into other residents’ rooms and going through their belongings.

### **Situation # 5**

**Beth** can’t sit still to eat her meals. She leaves the table without eating.

### SECTION IV QUESTIONS

1. Please define the “SOFT” approach

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2. Please match the behavior with the correct approach. The same approach can be used for different behaviors

1. \_\_\_ Combative

2. \_\_\_ Assaultive

3. \_\_\_ Wandering

4. \_\_\_ Physical  
Restlessness

5. \_\_\_ Sundowning

6. \_\_\_ Eating problems

7. \_\_\_ Sleep problems

8. \_\_\_ Yelling

9. \_\_\_ Sexual behavior

a. Make changes in  
Sleep/rest patterns

b. Soft approach

c. Distracting out of  
problem situations

d. Consider restrictive  
clothing

e. Avoid tranquilizers

f. Cue and reinforce quiet  
Behaviors

g. Use soothing music  
and touch

Combative with

3. Why is it more challenging to effectively use psychoactive medications with older persons and dementia residents than with younger persons?

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4. In what cases is it appropriate to use physical restraints?

- a. When a person is combative
- b. When a person is aggressive
- c. When a person is belligerent
- d. Never appropriate for behavioral reasons

5. Patients can become emotionally upset and frustrated when they are:

- a. Disoriented
- b. Rested
- c. None of the above
- d. A and B

**Book Resources for Behavior Section:**

1. The Best Friends Approach to Alzheimer's Care, V. Bell, D. Troxel. *A basic/general book on caregiving; very "approach" oriented and strong on training (including other "Best Friends....." books and training materials).*
2. The 36-Hour Day, N. Mace, P. Rabins. *The best-selling book of its kind – a basic/general book on Alzheimer's disease and dementia that includes behavioral pieces here and there (but not as strong as in that category as others).*
3. Gentlecare, M. Jones. *Maybe the best book basic/general book I've seen (although not easy to find), and very strong on behaviors.*
4. Understanding Difficult Behaviors, A. Robinson, B. Spencer, L. White. *A short practical book on dealing with behaviors. Good for training. Very dated, but I haven't found any newer books that do as good a job.*
5. Management of Challenging Behaviors in Dementia, E. Mahoney, L. Volicer, A. Hurley. *A more advanced book on the subject.*
7. Behaviors in Dementia: Best Practices for Successful Management, M. Kaplan, S. Hoffman. *Another more advanced book on the subject.*

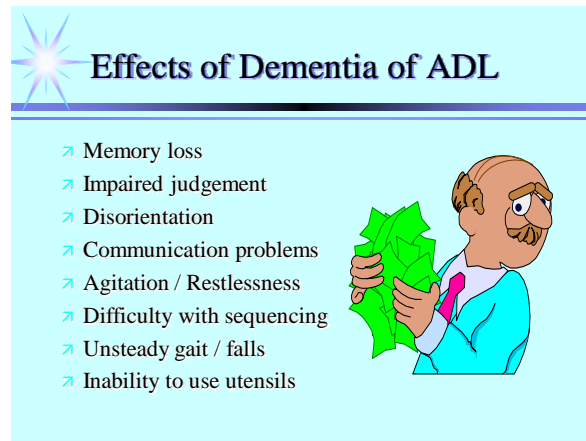
## SECTION V - ACTIVITIES OF DAILY LIVING (ADLS)

Activities of daily living (ADLs) are considered an individual's fundamental, self-care tasks. They include the ability to do the following:

- a. Dressing
- b. Eating
- c. Ambulating (walking)
- d. Toileting
- e. Taking care of hygiene needs (e.g., bathing, grooming)

In addition to ADLs there are the Instrumental Activities of Daily Living (IADLs). These activities are also important for the individual to function in the community and include the ability to shop, keep house, manage personal finances, prepare food, drive, and so forth.

### A. Effects of Dementia on ADLs



**Effects of Dementia of ADL**

- Memory loss
- Impaired judgement
- Disorientation
- Communication problems
- Agitation / Restlessness
- Difficulty with sequencing
- Unsteady gait / falls
- Inability to use utensils

The slide features a light blue background with a starburst graphic on the left. To the right of the list is a cartoon illustration of a man with a mustache, wearing a blue suit and a pink tie, holding a large stack of green banknotes.

#### 1. Memory Loss/Decreased Attention Span

- Forgets to complete ADL
- Forgets ADL has been completed
- Loss of interest due to distraction during ADL

**2. Impaired Judgment**

- Safety
- Privacy

**3. Disorientation**

- Forgetting people, time and place
- Unfamiliar people (inability to recognize loved ones)
- Emotional upset
- Frustration

**4. Decrease/Loss of Ability to Communicate**

- Difficulty/impossible to complete ADLs
- Loss of ability to reason or rationalize, leading to
  - ✓ Frustration
  - ✓ Agitation
  - ✓ Making task more difficult

**B. Other Problems that Affect Completion of ADLs**

**1. Sequencing**

- Inability to place in logical order

**2. Restlessness**

- Inability to remain still

**3. Difficulty or Inability to Perform Learned Motor Skills** even though motor function and comprehension are intact.

- Unsteady gait
- Increased falls
- Inability to coordinate use of eating utensils
  - ✓ Place your hand over the person's hand to offer support
  - ✓ Offer verbal cues.
  - ✓ Give small bites to get the individual started
  - ✓ Fill the spoon
  - ✓ Guide the elbow

**4. Abstract Reasoning**

- For a person with AD, if it can't be seen, it does not exist.

5. **Visual Spatial Skills** – loss of ability to use information to orient self and find destination. The person
  - May get lost
  - May not go into dark area
  - May not step on carpet or flooring of different color (usually a darker color)
  - May have a problem sitting (may miss the chair or toilet due to the inability to judge distance)
  
6. **Inability to Recognize, Name and Identify Objects**
  - Will describe something but can't find the right word
  - Will use the wrong word or say the same word for everything
    - It is okay to finish a sentence to decrease/prevent frustration

### C. Methods of Reducing Risk

Through training and experience, caregivers learn to:

- Anticipate problems or events
- Prevent problems or events
- Correct problems or events

Example: Discuss how incontinence might negatively impact the relationship between the PWD and family members as well as what behaviors might result.

## **D. How to Show Dignity and Respect to Persons with Dementia While Assisting with ADL's**

### **Dignity**

- Worthiness
- Conduct or manner indicative of self-respect

### **Respect**

- Courtesy
- Esteem
- Admiration
- Concern
- To refrain from intruding upon: Respect privacy

### **Know each resident you are caring for**

- Understand culture
- Understand generation
- Understand personal habits

### **Caregivers have traits and skills**

- Traits  
Distinguishing characteristics or qualities
- Skills
  - ✓ Ability to do something well
  - ✓ Expertness in performance.



## E. Caregiver Traits or “Knack” for Caregiving

- ◆ Some synonyms for knack are:

Talent	Skill	Savvy	Prowess
Mastery	Knowledge	Know-how	Expertise
Craft	Competence	Command	Capacity
Capability	Calling	Art	Aptitude
Ability	Proficiency	Brilliance	Flair
Genius	Gift		

- ◆ Elements of “knack”

### 1. Being well informed

- Learning as much as you can about the disease
- Learn caregiving tips
- Learn what community resources are available

### 2. Having empathy

- Imagine what it is like to have Alzheimer’s disease
- Understand the world of the person with dementia:  
Difficult, frightening, and real

### 3. Respecting the basic rights of the person

- Have value
- Deserve loving and high quality care
- Allow as much control in care as possible
- Try to keep them productive as long as possible

### 4. Maintaining caregiving integrity

- Approach problems and decision-making with an attitude of good will and out of concern and in the best interest of the person
- It may help to withhold information, e.g. simply saying “Come with me.”  
(Not saying where we are going or what we are going to do when we get there)  
Examples:     Doctor’s appointment  
                   Shower

### **5. Employing finesse**

- Respond to difficult situations with finesse
  - ✓ Skillful
  - ✓ Diplomatic
  - ✓ Tactful
  - ✓ Well-timed
    - Example: Answer “I want to go home.” with “Soon.”

### **6. Knowing it is easier to get forgiveness than permission**

- Caregivers occasionally must make decisions for the person with dementia that may cause a temporary upset
- An apology may diffuse a difficult situation, giving the person with dementia a sense of control

### **7. Using common sense**

- Seek simple solutions for complex problems
  - ✓ Remove caffeine from diet to prevent side effects of caffeine
  - ✓ Wash clothing when person is sleeping if it is upsetting to have clothes washed

### **8. Communicating skillfully**

- Help the person communicate better
- Listen
- Use positive body language
- Know the right and wrong ways to ask and answer questions
- Give cues to talk about lifetime interests
  - ✓ Life story

### **9. Maintaining optimism**

- Instill hope
- Take joy in small pleasures
- Remember the good times

### **10. Setting realistic expectations**

- Expectations that are too high or too low can be frustrating to the caregiver and to the PWD

### **11. Using humor**

- Laugh at funny things that happen
- Laugh at ourselves/Make fun of self
- Tell funny jokes or stories
- Laughter and good feelings are contagious

### **12. Employing spontaneity**

- Go with the flow

**13. Maintaining patience**

- Becoming frustrated or angry make things worse
  - ✓ It takes longer to accomplish tasks and respond to what is said or events that take place

**14. Developing flexibility**

- Go with the flow

**15. Staying focused**

- Put your own problems and concerns on hold
- Prevent distractions from preventing the provision of good care to the person with Alzheimer's disease
- Listen to what the person has to say
- Get the most out of every interaction you have with the person.

**16. Being nonjudgmental**

**17. Valuing the moment**

- Live in the present and value what is happening now

**18. Maintaining self-confidence**

- Know what you are doing
- Know that you are doing the right thing
- Have a plan of action

**19. Using cueing tied to the life story**

- Incorporate the life story into all aspects of caregiving

**20. Taking care of oneself**

- Find time for self as a caregiver
- Maintain friendships
- Exercise
- Eat a well balanced diet
- Have interests outside of caregiving

**21. Planning ahead**

- Help family caregivers plan for the future
  - ✓ Have financial and legal affairs in order
  - ✓ Plan for utilization of services

Source: Bell, V., Troxel, D. (1997). The Best Friends Approach to Alzheimer's Care (p. 94). Baltimore: Health Professions Press. Web site: [www.healthpropress.com](http://www.healthpropress.com); toll-free telephone: 1-888-337-8808; fax: 410-337-8539. Copyrighted material reprinted with permission from the publisher, July 2002.

## **F. How to Show Dignity and Respect**

- Provide privacy
  - ✓ Knock before entering & announce yourself
  - ✓ Close the door while assisting with personal care
  - ✓ Keep other residents and staff members from entering while assisting with personal care
  
- Limit choices
  - ✓ No more than 2 choices
    - Sometimes no choices, but make the person feel in control
  - ✓ Very difficult to make decisions
  - ✓ Allow to feel control when making choices
  
- Provide a structured environment
  
- Provide a routine (be flexible)
  
- Provide a consistency of caregivers
  
- Remember the “Knack”

## **G. Methods of Enhancing Independence and Preventing an Individual with Dementia from Losing Abilities**

### **1. Approaches to use**

- Establish rapport
- Talk in a calm voice
- Do not use reason or logic
- Don't rush
  - ✓ Allow enough time to complete the task.
  - ✓ Do not act as if you are in a hurry – the person will respond to your mood.

### **2. Encourage to do as much for self as possible**

- Give help before reaching point of frustration.
- Never take over an activity for an individual because the person is slow. This takes away independence.

### **3. Praise for small successes**

- Give compliments
- Give encouragement

### **4. Provide privacy**

- Respect modesty
- Remember generational needs

### **5. Do not keep the individual waiting**

- Have all needed items ready in advance

### **6. Demonstrate what you want done**

- Help start the task
  - ✓ Break tasks into small steps based on level of functioning
  - ✓ Sequence steps to simplify task

### **7. Stop when frustration occurs**

- Come back and try later

### **8. Make sure the room is**

- Well lit
- Clean
- Free of clutter
- Warm
- Use soothing music – resident's choice

**9. Find out preferences from family**

- Type of bath
- Time of bath
  - ✓ Establish a routine based on preference
- If you are unable to complete a task
  - ✓ Ask for help
  - ✓ Ask a co-worker to take over

**10. Provide assistive devices to encourage independence**

**11. Identify alternative approaches to providing personal care as the disease progresses**

**12. Environment should be comfortable and safe**

- Structured but flexible
- Consistency of caregivers
- Grouped according to functioning level

**Note: The following information provides an overview of each Activity of Daily Living and how Alzheimer's Disease impacts both the caregiver and the PWD in completing each task.**

## **H. Eating and Nutrition**

**1. Reasons why PDW have trouble eating:**

- Noise and commotion in the dining area
- Physical stressors such as anxiety related to 'going home', pain that has not been treated, discomfort, constipation, infection, acute illness, depression and other maladies
- Poor dentition (e.g. an abscessed tooth or ill-fitting dentures)
- Difficulty paying attention due to environmental distractions or a change in the environment routine or caregiver
- Poor attentiveness during eating related to fatigue
- Poor or inappropriate texture, the taste of food, or changes in food preferences, and/or
- The advancing disease process or related co-morbidities that may result in apraxia, dysphasia, or other deficits that compromise the eating process

## 2. **Building flexibility into the nutrition plan for a PWD**

When possible, include the person in the preparation process either through the planning or actual cooking of the meal, setting the table or serving.

- Identify what the PWD likes to eat.
  - ✓ Get a baseline history of their likes and dislikes from their family members or previous nutrition history.
  - ✓ Recognize cultural and ethnic food preferences.
  - ✓ Acknowledge any food allergies.
  - ✓ Elicit the support of interdisciplinary team to identify preferences and approaches.
  
- Develop a food plan that incorporates a variety of foods and fluids that the PWD enjoys.
  - ✓ Consider the full range of foods for taste (MyPyramid), textures, colors, hot/cold, and opportunities for presentation.
  - ✓ Identify the nutritional value of the food plan in order to meet estimated nutritional needs.
  - ✓ Include interventions that address distractions in the dining environment and caregiver approaches to feeding.
  - ✓ Also accommodate individuals that do not consume a variety of foods by offering foods that they will accept and tolerate.
  
- Initiate the food and fluid plan.
  
- Monitor the progress.
  - ✓ Ensure adequate intake and determine if the food and fluid selections are meeting the person's needs for "comfort", nourishment, weight, and hydration.

**3. Mealtime considerations:**

- Modify breakfast schedules to have food available when persons wake-up in the morning. By having food available at the time of rising, individuals may be more willing to eat.
- Start serving meals early for those persons who need more time to eat
- Use special devices and/or adaptive eating utensils to allow individuals to feed self as accepted (e.g. curved plates, sippycups, plates with lips, utensils with built up handles, and others)
  - ✓ Ensure the safe and effective use of these devices. Occupational therapy may help to assess the proper use of these adaptive devices.
- Provide encouragement and support
- Avoid stimuli overload by changing mealtime schedules and by minimizing or eliminating noise and other distractions
- Determine the correct temperature of the food that the PWD is most likely to eat
- Be flexible; what works one day may not work the next day

**4. Dining environment:**

- Make the dining environment as stress-free as possible (Vogelzang, 2003)
- Ensure adequate staffing to assist PWD with the dining experience and eating
- Ensure a non-rushed and unhurried environment
- Consider specialized or individualized dining experiences that are customized to meet the PWD's preferences
- Identify appropriate tablemates for persons to sit with
- Play soft and soothing music
- Use quiet tones of voice
- Have the eating area set at a comfortable temperature
- Think of food and memories
- Devise a dining system that allows for adequate supervision, but meets the needs of the PWD



**5. Snacks:**

- Identify snacks PWD enjoy related to the type of food, taste, consistency, and preferences
- Provide opportunities for the PWD to prepare his/her own snacks as appropriate
- Use foods and snacks that are nutritionally dense (CD-HCF, 2001).
  - Good examples include: sandwich halves, a variety of fruit, cheese cubes, pudding, and custard. Individuals may prefer snacks that are soft and sweet, like ice cream.
  
- Offer snacks periodically during the day
  - ✓ Nutritious snacks and foods are offered at least four (4) times a day: before, during, after activities and during the night, when a PWD is up and awake. It does not include the routine use of packaged saltine and graham crackers. Consider breakfast foods, such as oatmeal, for a nutritious snack.
  
- Offer shakes for those who eat less than 50% of their normal intake at a meal
  - ✓ Shakes are a good example of an easy alternative if meals are refused and in between meals. Examples include a fruit-smoothie, a milkshake with peanut butter and ice cream or other supplemental products that the PWD accepts and swallows. For those PWD with advanced dementia, consider a “Hydration Station” that offers fruit juices, water, and other beverages as well as a “Comfort Cart” for offering frequent servings of food and are available to PWD consistently throughout the 24-hour day. Consider the wide range of foods, accounting for taste and texture that an individual with advanced dementia will accept, swallow, and tolerate. Institute flexibility into the care planning process related to eating while providing adequate nutrition.

## 6. Weight loss:

Ensuring adequate nutrition is important at all stages of the disease process; however, advanced dementia presents the most challenges to caregivers. The following are approaches to monitoring weights and overall interventions to address weight loss.

- All PWD should be accurately weighed monthly to monitor for any significant weight changes
- Individual weights must be taken under the same conditions each time to assure accuracy. (Alzbrain.org, 2004)
- Provide good mouth care to enhance taste. (CD-HCF, 2001)
- Address challenges with individual food and fluid intake (e.g. recognition of dysphasia) and weight loss.
- Offer calorie dense foods and consider use of nutrition supplements for concentrated source of calories.
- Offer foods and fluids frequently throughout the day and optimize this when the PWD is most alert.
- Offer the larger meal at breakfast and noon if the PWD generally experiences poor food intake in the evening. (Vogelzang, 2003; CDHCF, 2001)
- Rearrange or reverse the normal eating schedule if the PWD eats larger amounts of food at different meal times during the day.

- Add condiments to add flavor and increase calories, if the PWD enjoys them. (Young, Binns & Greenwood, 2001)
- Consider offering several smaller meals during the course of the day rather than three 'traditional meals' and snacks.
- Use "assistive device" type foods, such as finger foods.
- As a last resort, medications that help stimulate the appetite can be considered. (Gallager, 2004)

**7. Feeding considerations, techniques, and approaches for those individuals with advanced dementia:**

- Pouching: small amounts of soft-textured foods that are more easily propelled by the pharyngeal muscles can reduce pouching (Frissoni, Franzoni, Bellelli, Morris, & Warden, 1998).
- Positioning the PWD: Assure correct posture with sitting upright to help with swallowing and strength of the upper body (Vogelzang, 2003). Make sure that the PWD is in the most comfortable position.
- Support self-feeding behaviors using hand-over-hand guidance at mealtime to reinforce the repetitive motion in self-feeding (Vogelzang, 2003).
- Dysphagia: Provide verbal or physical cues to stimulate swallowing. Check medications that may be causing sedation. Note the specific food that the PWD has difficulty with and alter the texture or omit the food item altogether (CD-HCF, 2001).
- Pace of feeding: The rate of which the meal is consumed should not exceed the swallowing and chewing capacity and capabilities (Vogelzang, 2003). Monitor and document in the care plan the optimal pace for a PWD.
- Refuses to eat: Place a small amount of food on the lower lip to stimulate interest in eating (CD-HCF, 2001). The loss of major functions such as the ability to sit up, show emotion, and swallow necessitates high-calorie foods that can be drinkable (milkshakes), hot cereal, high-calorie soups, or other products that can be pureed to a drinkable consistency. Fortified is better. Several very high-calorie supplements are available commercially.
- General wasting: Special care needs at the end-of-life include good oral hygiene and providing calorie-enhanced foods so that no bite or sip is ever wasted on a "non-caloric food" including beverages taken with medications. However, the focus is comfort care: give the PWD whatever they will accept and provide what is pleasurable for them.
- Encourage family members to become involved in the dining experiences by their active participation in assisting during meals and supportive care.
- Ensure good oral hygiene, as the PWD will accept.

## Section V – Activities of Daily Living

- Use the appropriate terminology to maintain dignity during the dining and feeding experience. Use the term “clothing protectors” instead of “bibs” and “dining program” instead of “feeding program.”
  
- Medical and physical considerations. The following can help:
  1. Primary Care Provider (Physician or Nurse Practitioner).
  2. Registered Dietitian.
  3. Nursing and direct care staff.
  4. Occupational Therapist.
  5. Speech and Language Pathologist.
  6. Dentist, and the
  7. Activity Program Coordinator.

## **I. Bathing**

1. Identify a bathing routine.
  - Is there a particular time that the PWD is used to bathing?
  - Is there a preference for a bath or shower?
  - Is the bathing environment soothing and inviting or cold?
2. In order to increase success in the bathing experience, be sure to have all necessary supplies available prior to bring the PWD into the bathroom.
3. Be willing to try alternative methods of bathing if attempts to provide baths and showers are unsuccessful.

## **J. Dressing and Grooming**

Dressing and grooming are very personal and private activities. The ability to carry out basic personal care, such as dressing and grooming oneself, is important for independent living as people age. However, for someone who has dementia, regardless of what stage, dressing and grooming presents a series of challenges. The ability to participate in dressing and grooming has been compromised. Most PWD will eventually lose the ability to participate in any meaningful way in these activities of daily living and will require total assistance from caregivers. Caregivers can use this as a unique opportunity and activity to provide comfort and connections with PWD in a respectful and dignified manner. The principles described in the approaches section serve as guiding principles related to dressing and grooming for a person with dementia. As with other activities of daily living, “knowing the person” – what they like and do not like – will help caregivers to make dressing and grooming enjoyable and engaging activities. In this document, dressing refers to the activity of putting on and taking off clothes and includes the consideration of footwear. Grooming refers to the activities related to a person’s personal hygiene and outward appearance.

### **1. Basic Principles and Approaches for Dressing and Grooming**

- Establish a routine that takes into consideration the best time of day when the PWD is used to dressing and grooming.
- ✓ Try to accomplish dressing at the same time each day as part of the daily routine (National Institute of Aging [NIA], 2002). Do not assume that the PWD knows what you are doing.

- Provide a comfortable dressing or grooming experience.
  - ✓ Go slow during dressing and grooming activities, using a gentle and respectful approach. Rushing or pressure during the dressing process may cause anxiety or agitation.
  - ✓ Be mindful of the time that it takes to dress or undress a PWD and their willingness to be or get dressed. Determine the best order of dressing. Use one-step instructions and break down the dressing task. PWD may need to rest intermittently, so provide breaks in the activity as needed. If necessary, caregivers may have to perform task segmentation or caregiving in bits of time, as the PWD may only tolerate part of the ADL task. If the activity is overwhelming or distressing, break it down into segments so that the activity remains comfortable and meaningful connections can be made.
  - ✓ Use two caregivers if a PWD cannot move their body on their own.
- Utilize a dignified approach to care.
- Always explain each step of the process to the person as you proceed with the activity.
- Speak to the person face-to-face, adjusting the tone of voice to benefit the person.
- If the PWD looks uncomfortable at any time, look for the source of discomfort and try to correct it.
  - ✓ Observe for any symptoms of pain and discomfort during dressing. Does the PWD resist care? Do they grimace, push the caregiver away or are unable to console? Look for signs of pain. Stop caregiving tasks if the person has pain and report the pain to their family members or their doctor. If the person routinely displays pain during grooming/ dressing activities, it may help if they take their pain medication one hour before the event.
- Be flexible; an approach that works one day may not work the next day
- Incorporate the PWD's past routine, whenever possible, into the current one
- If necessary, provide distraction to the PWD during caregiving
  - ✓ Sing or speak kind things or words to them.
  - ✓ Have them hold a comfortable object or consider giving them something pleasurable to eat and/or drink.
  - ✓ Use two or more caregivers to dress the person, if required.
  - ✓ Position the PWD to keep them comfortable during dressing and grooming activities, when necessary, such as using pillows and other types of equipment.

- Provide privacy, adequate lighting and warmth. In addition, it is important to avoid bright, glaring lights for the PWD. Draw the blinds or close the door for more privacy. Make sure that the PWD never feels cold or feels uncovered.

## 2. Considerations for Dressing and Footwear

- Choice of Clothing
  - ✓ Encourage the family to get clothing that can be easily removed for changing. Typically, one size larger provides greater ease for putting on and removing clothes. Watch for changing size needs due to weight gain or loss so that the clothes are not too big or small. With increasing impairment, try easy-care clothing such as sweat suits and pants or skirts with elastic waistbands, which may provide the greatest comfort. Consider comfortable clothing that the PWD can sit in. Also, choose pants that are not restrictive and achieve a comfortable fit. Front-opening shirts and blouses are recommended, particularly if the PWD has difficulty with items that go over the head.
- Consider the use of undergarments when providing comfort and support for women.
  - ✓ For example, a bra may be uncomfortable but a camisole or undergarment may be acceptable and more comfortable for a woman.

## 3. Special Considerations for Footwear

- Inspect the soles of the shoes for grip and treads and avoid any footwear with slippery soles.
- Check shoes periodically for proper fit, especially if the person has gained or lost weight or has diabetes or circulatory disease; ensure that the footwear does not impede circulation.
- Consider Velcro tennis or secure slip-on shoes versus tie shoes for ease of putting them on and taking them off.

#### 4. Considerations for Grooming

The primary grooming activities are hair care, shaving for men, using make-up for women, nail care, and mouth care.

- Hair Care
  - ✓ Determine the best time of day and approach to hair care
  - ✓ Keep the hair in an easy-to-care-for style
  - ✓ Determine the preferred means to washing the hair
  - ✓ Use no-rinse soap if the PWD is resistant to water and shampoo. If the barbershop or beauty parlor has been an important part of the PWD former routine, continue having him or her go to the place at a regular appointment time, if able.
  
- Shaving
  - ✓ Use shaving cream or other lubricants that genuinely moisten and lubricate the area being shaved.
  - ✓ Consider using hand-over-hand assistance to help the PWD to participate and connect with the activity of shaving.
  - ✓ Determine the best time of day and approach to shaving.
  - ✓ Use the method of shaving, electric or safety razor, which the PWD is most used to. If uncertain about the method, contact the family to ascertain the PWD preference and life-long habits.
  - ✓ Use only high-quality disposable safety razors.
  
- Nail care
  - ✓ Consider a beauty event for a day featuring hand or foot massages, while attending to nail care.
  - ✓ Move slowly during the procedure and tell the PWD what is going to happen with each step of the activity.
  - ✓ Trim/file fingernails and toenails at least twice a month and as needed.
  
- Oral hygiene
  - ✓ Ideally, teeth should be brushed two to three times a day in order to remove the plaque that causes tooth decay with a minimum standard being once a day



- ✓ If a PWD has dentures, seek continued care and regular check-ups for gum and bone health
- ✓ Poorly fitting dentures can contribute to poor nutrition and may result in weight loss, infections, constipation, and mouth sores. If this occurs, dietary staff can re-evaluate the diet and food consistency.
- ✓ Take out the dentures at bedtime and place them in a denture cup with
- ✓ water or other preferred cleaning solution
- ✓ Consider using mobile dental services for regular check-ups or any
- ✓ other dental concerns, as it will be easiest on these individuals

## K. Toileting

This section begins with background information on incontinence and an explanation of terms. Caregiving techniques follow these explanations.

### Urinary and Fecal Incontinence

If incontinence is a new problem, the PWD's primary care provider can determine if there are underlying medical reasons. Although individuals with advanced dementia will eventually lose independent control of their functions, many causes of incontinence can be controlled in earlier stages of the disease process.

- Primary care Providers can assess potentially reversible causes using the DIAPPERS system (Lekan-Rutledge & Colling, 2003):
  - **D**elirium, dementia, depression
  - **I**nfection (urinary tract infection)
  - **A**trophic vaginitis
  - **P**harmaceuticals
  - **P**sychological, pain
  - **E**xcess fluid (polyuria, edema)
  - **R**estricted mobility
  - **S**tool (constipation)

**Timed voiding** is toileting the PWD every 2-3 hours on a fixed schedule. The goal is to decrease bladder volume with corresponding decrease in stimulus to void between toileting and lower volume wetting if incontinence does occur. Two descriptive studies found an 85-91% improvement in incontinence (Wells, 1997).

**Habit retraining** is patterned urge-response toileting. A bladder-emptying pattern is determined through pant checks or electronic sensor monitoring systems. This way a toileting schedule can be individualized rather than set to a fixed and arbitrary time. Little research has been done but one study found an overall 86% improvement in control with one third of persons improving by 25% or more with this approach (Wells, 1997).

**Prompted voiding** is a technique that combines routine toileting on a 1-2 hour frequency with person-directed communication and social reinforcement of bladder cues. Research has shown an overall 75% improvement, with about one third of persons decreasing incontinence to less than once in 12 hours (Wells, 1997).

**Bowel programs** to prevent constipation need to be individualized to take into account body size and nutritional intake. A daily bowel movement is not a realistic goal for frail elderly persons with advanced dementia.

**Fecal incontinence** occurs late in advanced dementia. Loss of bowel control in the early stages of dementia suggests some physical problem, such as damage to nerves that control the rectal sphincter, severe disabling hemorrhoids, or rectal tumors.

**Fecal obstipation** is a massive accumulation of feces within the colon that occurs with dehydration, low fiber diet, the use of anticholinergic medications as well as recurrent rectal impaction. Long-term users of antipsychotic medications are at a higher risk for developing fecal obstipation. Assessment is done through rectal examination and physical assessment to palpate the colon as well as flat plate of abdomen to demonstrate copious amounts of hardened feces within the colon. This condition requires dietary monitoring, good hydration, and consistent bowel cleansing to correct the bowel dysfunction (Alzbrain.org, n.d.).

**“Digging”** at the rectum occurs for some PWD and may result from hemorrhoids, impaction, or skin problems in the perineal area. Females may dig at the rectal region because they have vaginal infections such as Candida following antibiotic therapy or thinning of the skin of the vulva due to estrogen deficiency. Males may dig at the rectal area because of hemorrhoids or impaction. Any PWD digging at their rectal region should have careful perineal examination and women should have vaginal examination to exclude other causes of perineal discomfort (Alzbrain.org, n.d.).

## 1. Managing Urinary Incontinence

- Ensure that adequate ‘cues’ exist to identify the location of the bathroom.
  - ✓ Consider posting a written sign or picture.
  - ✓ Identify, if possible, physical behaviors that may indicate the need to use the bathroom and ensure that the PWD is directed to the bathroom as soon as these behaviors occur.
  
- Set a toileting schedule.
  - ✓ A common practice is to encourage toileting for the PWD every two hours while awake but some may be able to do every 3 or 4 hours.
  - ✓ Caregivers need to assist with each step of the process. Discuss, for example, how toileting a PWD would include the following:
    - Leading the PWD to the bathroom or a bedside commode (BSC);
    - Assisting with disrobing;
    - Positioning the PWD comfortably on the toilet or BSC; and,
    - Monitoring to assure the PWD does not prematurely stand and leave the toilet.

- Determine the person's natural toileting routine.
  - ✓ Keep a written record of when the PWD goes to the bathroom as well as when and how much he or she eats and drinks.
- If the person is unable to travel to the toilet, use a bed side commode.
- Toileting should be done with respect for the person's privacy and dignity.
- Assure that good perineal care has been provided.
- Assure post-toileting hygiene is complete by assisting PWD with handwashing.

## 2. Maintaining Bowel and Bladder Function

- Do not withhold fluids when the person starts to lose bladder control.
- Eliminate caffeinated drinks.
  - ✓ Beverages with caffeine such as coffee, cola and tea act as diuretics and can stimulate urination. Offer choices between caffeinated and decaffeinated, as able.
- Limit liquids at least 2 hours before bedtime but be sure to provide adequate hydration throughout the day.
- Use absorbent and protective products such as adult briefs during the day and bed pads at night as a backup to the toileting schedule.

- Monitor the frequency of bowel movements.
- Provide reminders to those who may forget to use the bathroom.
- Watch for visible cues that may exhibit the need to use the bathroom.
  - ✓ Common signs may include restlessness, anxiety, agitation, pacing, unusual sounds, facial expressions, sudden behavioral changes when no other cause is evident, pulling at their clothes, dropping their pants, and/or suddenly stopping eating for no apparent reason.

### **3. Handling Incontinence**

- Be supportive by helping the PWD retain a sense of dignity.
- Respect the privacy of the PWD by “looking the other way” if the PWD appears to be uncomfortable by your presence.
- Dress the PWD in manageable and comfortable clothing.
- Use adult briefs and protective pads as needed.
- Use adaptive clothes specially designed for impaired adults.
- Sleep clothes should be functional as well as comfortable.
- Use incontinence bedding.

**SECTION V QUESTIONS**

1. ADL's are affected by dementia and include:
  - a. Unsteady gait
  - b. Falls
  - c. Anger
  - d. A and B
  
2. Some of the reasons why the patients cannot complete ADL's are:
  - a. Inability to place steps in logical order
  - b. Unsteady gait
  - c. Increased Falls
  - d. All of the above
  
3. How do we reduce risk for ADL's completion?
  - a. Anticipate, prevent, correct
  - b. Assist, cue, prevent
  - c. Assist, correct, prevent
  - d. Anticipate, assist, cue

4. Give and describe 5 elements of Knack

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5. One of the ways to show dignity and respect is to limit choices.
  - a. True
  - b. False

6. Please give 3 ways to enhance independence and explain.

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## SECTION SIX - ACTIVITIES

In this session, you will learn that activities are the foundation of care. Every event, encounter or exchange is an activity. The scope of activities includes every interaction with staff, volunteers, relatives and other individuals; not only scheduled events provided by staff. (Excerpt from Activity Based Alzheimer Care). In addition, you will determine methods for assisting families to cope with the reality of Dementia.

Objectives: At the end of this session, you will be able to:

1. Understand what activities make up a person's daily experience and should reflect as much as possible, that person's preferred lifestyle.
2. Learn what will enable a sense of usefulness, pleasure and success in as normal a level of functioning as possible.
3. Be able to provide meaningful and appropriate activities that are person-centered and that all caregiving should be treated as meaningful/engaging activities.
4. Enable families to deal with the changes that will occur in the disease process and to give them a means of support and resources.

### Key Principles

- Meaningful activities reflect a person's interests and lifestyle.
  - Activities should be voluntary
  - Activities should be purposeful
  - Activities should be socially appropriate
  - Activities should offer some amount of success
- All caregiving should be treated as meaningful and engaging activities.
- Incorporate daily living skills into meaningful activity, i.e., setting the table, helping with laundry and other various household or yard tasks.
- Activities should be enjoyable.
- Activities should make a person feel useful and provide a sense of belonging.
- The importance of knowing your resident when planning activities so that they are appropriate and respect their interests as well as their beliefs, culture, values and life experiences.
- How to approach and work with your resident to do an activity successfully.
  - Use the soft approach
  - Have a pleasant look on your face
  - Be an encourager
  - Be supportive and step into their world of dementia

## A. Types of Activities

### Key Definitions

- Activity: The things we do
- Ability: What a person can do
- Failure-free activity: An activity that cannot be done incorrectly. The purpose is to make meaningful connections, to increase feelings of self-worth and to have fun

### The Alzheimer's Association Activity Philosophy –

The activities that make up a person's daily experience should reflect as much as possible that person's preferred individual lifestyle while enabling a sense of usefulness, pleasure, and success at as normal level of functioning as possible.

(Source: Alzheimer's Association Activity Based Alzheimer's Care: Building a Therapeutic Program)

### "Activities" Exercise

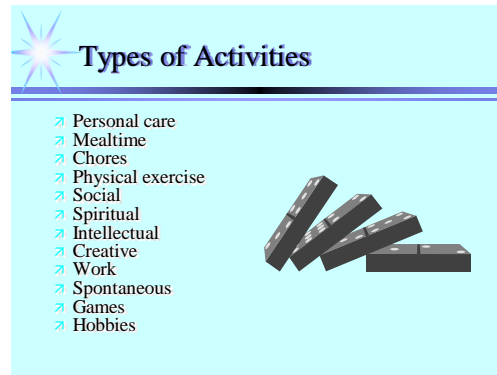
1. Write five of your favorite activities you do when not working.
2. Tell your neighbor why you enjoy these activities.
3. Imagine not being able to do the activity that you love the most.
  - How would your life change?
  - Who else would be affected by this loss?
  - How does this make you feel?

Alzheimer's disease is a progressive degenerative disease. The person with dementia (PWD) has difficulty or is unable to do the things that she/he enjoyed doing. It is important to note that meaningful activity is beneficial for the person with PWD. Activities of daily living, daily interaction with family and caregivers are all part of providing successful experiences and moments for the person with memory loss. **Remember, everyone who works or interacts with a person who has memory loss, is providing an activity.**

***👉 Instructor Note: If time allows let participants discuss the following questions in small groups and then report.***

- What have you observed in your residents when doing activities?
- What do you observe when their day does not include structure or purpose?

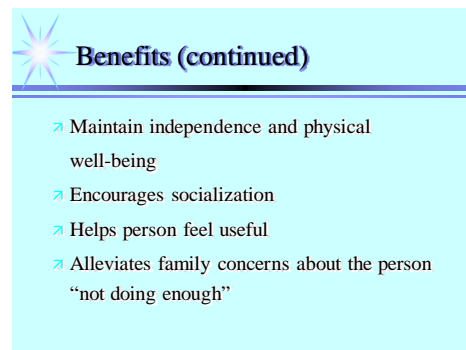
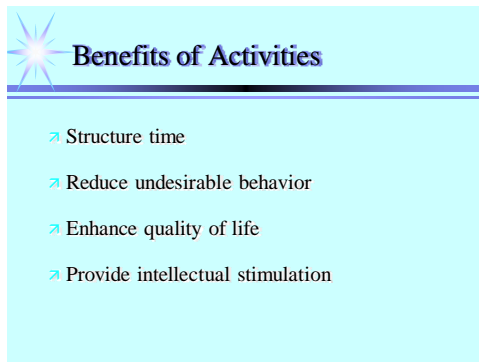




The activities listed below are designed as part of the social model of care, or the Activity Based Alzheimer's Care (ABAC), where **everything** is deemed an activity. They add variety to the resident's day. These activities promote interaction, encourage creativity, provide exercise and add quality of life to the person with PWD or other dementia. They include:

Personal care	Mealtime	Physical	Sensory
Household Tasks	Exercise	Social	Spiritual
Intellectual	Creative	Games	Music
Spontaneous/Flexible Hobbies			

**B. Benefits of Activities**



- Structures time and makes the best of remaining abilities
- Helps to reduce undesirable behaviors, associated with diagnosis of anxiety, agitation, or depression
- Are diversional and enhance quality of life
- Provides mental stimulation
- Helps maintain independence and physical well being
- Encourages socialization
- Helps person feel useful and needed
- Provides reassurance to families that their loved one is being integrated into the life of the facility while leisure interests are being met
- Enhances sensory awareness
- Provides sensory calming

## C. Guidelines for Choosing Activities



- The guidelines for choosing activities include selecting activities that are interesting, by considering the person, the activity, the approach and the environment.
- The caregiver will need to be flexible since the PWD may enjoy an activity one day and reject it the next day.

**!!!! Do What they Like and Do it Often!!!!**

## D. How to Determine Appropriate Activities:

### 1. The Person with Memory Loss

- Male/female
- Medical Information
- Family History
- Social/Cultural Information
- Religious/Spiritual
- Work History
- Interests/Abilities
- Needs – What does this person need help with?
- Strengths – Remaining Capabilities
- Person's best time of day
- Personal Values

### 2. The Activity

- Is it failure-free?
- Does it involve others?
- Does it use the resident's abilities?
- Will it help maintain independence?
- Is it fun?
- Is it person-appropriate?
  - ✓ If an activity is enjoyable to a person and has meaning to him/her, then it is appropriate (remember ABAC)

- Is it purposeful? – Every activity has meaning. When there is no meaning or purpose, people will not want to do it. No one wants to do something without purpose or meaning, even if that meaning is to have fun or diversion.
- Only adapt what needs to be adapted.
- Is it simplified?
  1. Reduce number of steps to be taken (ABAC)
  2. Increase types and frequency of cueing (verbal, visual and hands-on assist) (ABAC)
- Is it voluntary and not forced?
- Do we need to change the activity to make it work?
- Cluster groups of PWD according to abilities, strengths and interests (ABAC)
- Always be flexible and have something else to do if the first activity doesn't work.
- How long will activity last? (Activities don't need to be 60 minutes long. They can be done in shorter increments, i.e., 20-30 minutes for some and 30-45 minutes for others. As the disease progresses, 10-20 minutes may be appropriate.)
- If a group, how large should it be?
  - 8-10 for beginning stage
  - 6-8 for moderate stage
  - 2-4 for advanced dementia

This is not to say that certain people cannot attend large group functions, i.e. special events, music programs. However, PWD who function better in smaller groups should be offered those opportunities. This is where connections with your residents are made. Without a connection, there is no real value or response to many of the activities provided.

### 3. The Approach

#### **What equipment do I need? – Plan ahead and be ready.**

- Keep steps simple. You can make an activity child-like by simplifying processes, but the activity should never be childish which means you are degrading and treating your residents like children.
- Remain positive
- Step into their world and join their journey
- Do not criticize, correct or disagree
- Be consistent
- Structured, yet flexible; which will reduce anxiety and confusion Do not become rigid (ABAC)
- Provide supervision and engage with participants
- Respond to verbal and non-verbal feelings
- Let person know he/she is needed and appreciated

#### 4. The Environment (the Milieu)

- Free of distractions and safe with no dangerous objects
- Don't make the nurse's station the main focal point, but make the PWD's living space and day areas feel like home instead of a sterile environment
- Living space should be: normal, homelike, non-technological, warm, avoidance of patterns, comfortable with objects and pictures that feel .....**just like home**
- Have interactive equipment and items for the PWD to explore instead of a sterile environment
- Manipulate the environment to achieve program and individual goals through the use of:
  1. Furniture color
  2. Objects and sound
  3. Cultural themes
  4. Activities with a theme
  5. By creating a mood or atmosphere
- People can hear and see each other (Form groups at table, semi-circle or circle)
- Alternate activities are available if needed (Be flexible)
- Do you have enough help for this activity? Adequate lighting and space (Source: F Tags 248 & 249 of CMS Interpretive Guidelines)
- Comfortable
- Use proper positioning of PWD (F Tags 248 & 249)
- Leave objects in sight and do not lock up. In other words, tables in day areas should have stimulating activities to create independent activities, i.e., baskets of sorting (beads, materials, laundry, flowers, sanding wood, etc.)
- Use giant fabric flowers, animals and interactive objects on walls. Some will use antiques to create an environment similar to backgrounds of their residents.
- Enlarge photos – especially familiar ones.
- Use plants and animals.
- Provide rummage opportunities wherever and whenever possible
- Compensate for sensory deficits:
  1. Place interesting, fragrant, textured, visually attractive objects within reach.
  2. Do not lock objects of interest up in cupboards or closets.
  3. Celebrate the person's competency and remaining function by providing them with normal, everyday activity.
  4. Use of life panels or family portraits by involving families.
  5. Revamp mealtimes to accommodate individual residents needs and offer food 24/7 and not just 3x's per day
- Know who you are designing for – all designs should be for the PWD and their families.
- Create Activity Domains or Reminiscence Domains with a purpose to offer our residents the opportunity to evoke certain memories through reminiscing.
  1. Housekeeping Closet with feather dusters, dust mops, brooms, dust cloths, etc.

2. Childcare or Baby domain with a bassinet, life-like baby dolls, christening gowns, glider rockers, shelves with baby paraphernalia, baby buggy, blankets, diapers, baby clothes.
3. Office domain – with desk, old typewriter, files, papers, pens, old check books or ledgers. (same can be done for school teachers)
4. Personal care domain – jewelry, coat racks, hats, neckties, jackets, gloves (for men and women). You can also decorate with attire from various eras.
5. Create your own according to the interests and backgrounds of your residents.

## **E. Activities for Different Stages of Dementia:**

**Early Stage Activities** are used for socialization with caregivers, family and friends. These activities are extensions of the interests of the person and help to maintain their abilities and feelings of self-worth.

Provide real life activities similar to backgrounds of clients:

1. Household activities, i.e., cooking, cleaning, decorating for holidays
2. Music, entertainment, song-writing, games, i.e., Music Bingo, cards, arts/crafts
  - a. Simplify as needed - do not use children's equipment and toys
  - b. Refer to senior activity suppliers for equipment for elderly use
3. Physical – ball toss, movement to music, parachute fun, golf, and other adapted sports
4. Reminiscence – Trivia, Word games, Movies, Music
5. Games – Bingo, cards, bowling, target fun, word games
6. Creative – cooking art, crafts, song-writing, poetry, story writing, gardening
7. Mental – reading, current events, giant crosswords, word finds
8. Spirituality - bible study, church services, prayer, scripture, music
9. Provide times for relaxation
10. Movies, musicals, old westerns, comedy (for example, I Love Lucy) from their era

**Middle/Moderate Stage Activities** are modified to accommodate their abilities and their interests at this stage.

1. Clustering is important at this time where similar interests and abilities are gathered into smaller groups (6-8)
2. Avoid over-stimulation
3. Simplify projects such as crafts, games, art, adaptive sports.
4. Use music to evoke memories and interactions and to just have fun, as well as use music to exercise to

5. Provide diversional activities for independent participation when groups are not available or when smaller groups are being run by leader:
  - a. Folding
  - b. Flower arranging
  - c. Diversional Baskets
  - d. Activity Domains (childcare, office, workbench, beauty and grooming areas, etc.)
  - e. Sorting of jewelry, beads, laundry, buttons
  - f. Simple non-harmful crafts
  - g. Reading materials
  - h. Picture albums
  - i. Sensory items using material, scrapbooks, etc.
    1. Spirituality – music, prayer cards, pictures, scriptures, prayer
    2. Gardening
    3. Pets
    4. Lotion and relaxation
    5. Movies – old westerns, old comedies (Red Skelton, I Love Lucy, Andy Mayberry RFD), musicals (Broadway musicals, Gene Kelly, Fred Astaire)

**Advanced Dementia Palliative Care Activities** should provide comfort, sensory enhancement and sensory calming.

1. Goals of Palliative Care for Advanced Dementia
  - Anticipate and meet comfort needs such as hunger and thirst, proper positioning, continence issues, agitation and pain
  - Provide meaningful interactions with activities that focus on stimulating the resident's senses (smell, touch, taste, hearing, vision (quality of life)
  - Promote spirituality through the use of music, songs, scriptures and poems (quality of life)
  - Utilize the resident's life story to personalize care and interactions (dignity)
  - Create a warm, homelike environment in each resident's room and the general nursing unit (milieu)
  - Sensory Enhancement and Sensory Calming, i.e., Snoezelen Approach from Flaghouse, Inc. ([www.snoezeleninfo.com](http://www.snoezeleninfo.com)); Multi-Sensory Environment (MSE) from TFH USA, and other programs available for seniors.
    - a. Lotion and Music
    - b. Pet Visits and live-in pets. (Dogs on leashes may be small, but live-in dogs should be tall and within PWD's line of vision.)
    - c. Sensory videos
    - d. Music to elicit responses and for comfort.

2. Changing the Culture of Care for Advanced Dementia

**Old Culture vs. New Culture**

- a. Task focused vs. resident focused.
- b. Reacting to needs vs. anticipating needs
- c. View behaviors as “just the way they are” vs. view behaviors as unmet needs
- d. Group activities vs. individualized activities to make connections
- e. Traditional mealtimes vs. 24/7 meal and snack times
- f. Social history incomplete vs. life stories known on all residents
- g. Demanding milieu vs. comfortable surroundings

**F. Activity: Planning for Failure Free Activities**

**Activity Steps:**

- Write the name of a PWD you care for: \_\_\_\_\_
- Identify five things you know about this person:
  - 1.
  - 2.
  - 3.
  - 4.
  - 5.
- Write down three needs of this person:
  - 1.
  - 2.
  - 3.
- Write down 3 abilities of this person:
  - 1.
  - 2.
  - 3.
- Discuss who this resident is, his or her strengths and needs, and some possible activities her or she would enjoy.
- Write down your selection(s) below:

**SUMMARY: When considering doing activities with PWD, do what they like, and do it often!!**

### SECTION VI QUESTIONS

1. A failure-free activity is what a person can do
  - a. True
  - b. False
  
2. In choosing activity, flexibility is a must as residents may enjoy an activity one-day and reject it the next day
  - a. True
  - b. False
  
3. The environment/Milieu for activities should be:
  - a. Free of distractions
  - b. Normal, homelike
  - c. A sterile environment
  - d. A and B
  
4. At the early stage of Alzheimer's, activities should be real life activities such as cooking and cleaning similar to backgrounds of clients
  - a. True
  - b. False
  
5. At the Middle/Moderate stage of Alzheimer's, the PWD should do similar activities than PWD at the early stage. Activities should include cooking and cleaning.
  - a. True
  - b. False
  
6. At the Advanced stage of Alzheimer's, activities consist of use of music, sense of smell, scriptures and poems.
  - a. True
  - b. False



## **SECTION SEVEN - LEGAL AND FINANCIAL PLANNING FOR FAMILIES**

### **Topics covered in this section:**

- Capacity Issues
- Power of Attorney (POA) and Surrogates
- Guardianships
- Conservatorships
- Medicare vs. Medicaid (ALTCS)

### **Capacity Issues:**

Legal considerations begin with a determination of whether or not a person has capacity. Generally speaking, capacity is the ability to understand the nature of an act and the effect of the act. In other words, a person must have the ability to understand the decision he/she is making.

Example: To have the capacity to create a Health Care Power of Attorney (HCPOA), a person must be able to understand that a HCPOA will allow someone else to make medical decisions, and also understand that by signing a HCPOA, someone else will in fact make those medical decisions when the person cannot make them personally. Different documents may require different levels of capacity.

### **A. Power of Attorney (POA) and Surrogates:**

After reading this section you will be able to:

- Define the purpose of a Health Care Power of Attorney
- Recognize the authority given to a Mental Healthcare Power of Attorney
- Understand the laws surrounding a Financial Power of Attorney
- State the priority order of surrogates if there is no guardian and no agent under a Health Care Power of Attorney
- Understand the purpose of a living will
- Define the difference between a customary will and a holographic will
- Understand the distribution of a person's assets if he or she does not have a will

### **Healthcare Power of Attorney:**

A Health Care Power of Attorney (HCPOA) is a written document that allows a person (the principal) to designate someone else (the agent) to make health care treatment decisions for the principal if the principal becomes incapable of doing so. The HCPOA must clearly declare the principal's intent to delegate the power to make health care decisions. The HCPOA must be signed by a principal who understands the ramifications of naming an agent and is free from duress. The HCPOA must also be witnessed by at least one adult who is not the agent, relative, heir of the principal, or directly involved in providing health care to the principal.

The principal should choose an agent who is trustworthy and who will be willing to make the necessary health care decisions. It is also important to name a secondary agent in case the first is unable or unwilling to act as the agent. The principal should give a copy of the HCPOA to the physician and to the agent so that, if necessary, the agent can exercise the decision-making authority. As long as the principal has sufficient capacity, the HCPOA may be revoked or changed.

### **Mental Health Care Power of Attorney:**

Arizona law also recognizes a Mental Health Care Power of Attorney (MHCPOA), which is a written document that allows a person (the principal) to designate someone else (the agent) to make mental health care decisions for the principal. The MHCPOA can specifically authorize the agent to consent for the principal to obtain inpatient mental health care and treatment. The MHCPOA is especially important because it is the only way an incapacitated person can be admitted for inpatient mental health treatment unless a guardianship is obtained that authorizes the guardian to obtain the inpatient treatment. As long as the principal has sufficient capacity, the MHCPOA may be revoked or changed.

Having both a MHCPOA and a HCPOA will maximize a person's chance of avoiding court involvement, which is more restrictive, expensive and time consuming.

Note: The MHCPOA can be a separate document. Alternatively, specific provisions of the MHCPOA can be incorporated into the regular HCPOA so that one document takes care of both medical and mental health issues.

### **Financial Power of Attorney:**

A Financial Power of Attorney (FPOA) is a written document that allows a person (the principal) to designate someone else (the agent) to make financial and legal decisions for the principal. A principal must be capable of understanding in a reasonable manner the nature and effect of signing the FPOA at the time the FPOA is signed. The principal must also sign willingly and without being coerced. Many times, when an agent needs to assume the duties granted under a principal's FPOA, the principal is no longer capable of making a new FPOA. Therefore, if the provisions in the FPOA executed by the principal do not comply with the law, or if the provisions are insufficient, a conservatorship may need to be established to manage the principal's assets. Because of the strict nature of the laws regarding FPOAs, it is recommended that an attorney be consulted.

Arizona, and most other states, has specific requirements governing the execution and use of a FPOA. The principal must sign the document and initial any paragraphs where a benefit to the agent is authorized. In addition, a witness and a notary public must also sign the document. The witness and the notary must be different people. The witness cannot be the agent, the agent's spouse, or the agent's children. As long as the principal remains competent, a FPOA can be revoked or changed.

In the last few years, Arizona laws about FPOA's have become stricter:

- The agent must use the principal's assets only for the benefit of the principal.
- The agent is not entitled to use the principal's property for the agent's benefit. Any paragraph granting such authority in the FPOA must detail the benefit and it must be initialed by the principal and a witness when the FPOA is signed.
- If the agent does take a benefit from the principal's assets that is not approved within the FPOA, the agent is subject to criminal charges and, if the agent is a potential heir of the principal's estate, the agent can lose the right to inherit.

It is important to note that some banks and financial institutions may be reluctant to accept a particular FPOA, and there is no formal oversight of the agent acting under a FPOA. Most banks and financial institutions carry their own Special Power of Attorney form. The individual may want to execute the Special Power of Attorney from their bank/financial institution in addition to a general FPOA.

A FPOA can be a useful tool that allows a trusted person to handle their loved one's financial affairs. If there are no family members or close friends available to be the agent, a private fiduciary licensed by the state may be willing to act as agent. If a valid FPOA exists, the agent acts in a trustworthy fashion, and the principal will allow the agent to act, a conservatorship can be avoided in most cases.

### **Surrogates (Alternative to Guardianship):**

All of us want to make our own decisions, and as long as we have sufficient capacity, we have the legal right to make our decisions. If we become incapacitated, however, and no longer have the understanding to make or communicate our decisions, the law allows a court-appointed guardian to be the first priority as an alternate decision maker. Following the court-appointed guardian, the agent under a Health Care Power of Attorney (HCPOA) is next in priority. If there is no guardian and no agent under a HCPOA, then the law gives priority to the following persons, in the order given:

- The person's spouse (unless they are legally separated)
- The person's adult child (If the person has more than one adult child, then a majority of those reasonably available are to be consulted)
- The person's parent
- The person's domestic partner if the person is not married and if no one else has accepted financial responsibility
- One of the person's brothers or sisters
- A close friend of the person who has shown care and concern for the person and who has knowledge of the person's views and wishes for health care
- The person's attending physician if no one else can be located

Although these surrogates may obtain ordinary health care treatment, a surrogate who is not the agent under a HCPOA or who is not a guardian cannot make the decision to withdraw the artificial administration of food or fluid, and cannot obtain inpatient mental health care and treatment except on a limited emergency basis.

### **Living Will:**

The individual's "Living Will" (LW) must be considered when determining a course of action. If no LW exists, then the expressed wishes of the individual must be followed. If the individual completes a LW, the Agent or Health Care Power of Attorney can not make any changes to the LW.

Example: Your mother is living in a nursing home and has completed a LW, which states all should be done to sustain life. Shortly after your mother completes her LW, her health status takes a turn for the worse and she is no longer able to speak and requires 24-hour care. The Health Care Power of Attorney can not change the LW, to state Do Not Resuscitate (DNR). If a client already has a LW in place, and then becomes incapacitated nobody can make any changes to the individual's LW.

### **Wills:**

A Last Will and Testament, often referred to as a (Will) is a document that allows a person (the "testator") to designate who will get the testator's property when he/she dies. Arizona does not recognize "oral wills". Ideally, the "Will" also names a Personal Representative ("executor") to initiate the probate process and to manage the estate, payment of debts and taxes, and the distribution of assets to those designated to get them under the terms of the "Will".

Arizona recognizes that a competent adult, someone of sound mind, can make a "Will." The testator must be able to identify his/her property, must know the natural objects of his/her bounty (family members, close friends), and must understand that a "Will" is being created, which will give the property to the persons or entities identified in the "Will".

Arizona recognizes holographic wills (HW). A HW is one where the important provisions are written in the testator's own handwriting and bearing the testator's signature (a date on this document is recommended). A HW does not need to be witnessed by third parties.

The customary will (CW) is one that is typed up or that is prepared by an attorney. Any "Will" that is not written in the testator's own handwriting must be witnessed by two people. Often the witnesses will sign the "Will" in the presence of a notary as well.

"Wills" can be revoked at any time the testator has a change of mind, as long as the testator is still of sound mind.

### **What happens if I don't have a Will?**

In Arizona, when a spouse dies (the "decedent") without having a "Will" ("intestate"), all of that person's property generally goes to the surviving spouse. However, if the decedent had children from another marriage, half of the decedent's separate property and the decedent's half of the community property goes to the children of the other relationship. The surviving spouse gets his/her own half of the community property and the remaining half of the

decedent's separate property. Arizona law also dictates the disposition of the decedent's property if the decedent had no surviving spouse or children.

**Out of State Directives:**

A Health Care Power of Attorney (HCPOA) prepared in another state is valid in Arizona if it was valid in the state it was made. Nevertheless, if the HCPOA does not look like those typically seen in Arizona, the medical care provider may be reluctant to accept the document. The prudent person may want to ask a qualified attorney to review the directives to determine their validity.

**Power of Attorney (POA) and Surrogates - Review Questions**

- What is the difference between a Health Care Power of Attorney and a Mental Health Care Power of Attorney?
- Can you have a Health Care Power of Attorney and a Mental Health Care Power of Attorney at the same time?
- What must a principal do on the document once all the benefits of an agent are outlined?
- When do the person's children have the power to act as a surrogate?
- What types of "Wills" does Arizona recognize?
- What happens when a person does not have a "Will"?
- When is a Health Care Power of Attorney made in another state recognized in Arizona?

**B. Guardianships:**

After reading this section you will be able to:

- Define guardian
- Discuss when a guardianship is necessary
- Understand the responsibilities of a guardian
- Understand how a guardian is appointed
- Define different types of guardianship, including "mental health" guardianship

**What is a guardian?**

A guardian is an individual appointed by the court to make personal decisions for someone else who is called the "ward." A guardian has powers similar to those of a parent for a child, although the guardian is not required to provide financial support for the ward from the guardian's own funds. A guardian makes decisions about where the ward will live and what kind of medical care the ward will receive.

**When is a guardianship necessary?**

A guardian may need to be appointed for a person who does not have enough understanding or capacity to make or communicate responsible personal decisions. The incapacity may be due to mental or physical illness or disability or the chronic use of drugs or alcohol. Family and friends should evaluate answers to the following questions:

- Does my loved one have difficulty doing familiar tasks?
- Can my loved one communicate coherently?
- Does my loved one know what medications he/she is taking, and is my loved one taking the medications appropriately?
- Does my loved one have extreme mood swings for no apparent reason?
- Does my loved one become easily agitated, aggressive, or combative?
- Does my loved one often lose things or put things in inappropriate places?
- Does my loved one often forget where he/she is?
- Can my loved one attend to and provide for necessary food, shelter, clothing, and medical care so as to avoid physical harm or illness?
- Can my loved one keep safe in stressful or emergency situations such as fire, power outage, or crossing a busy street?

Sometimes a loved one has a Health Care Power of Attorney (HCPOA) in place, authorizing someone else to make medical and placement decisions when the loved one is not able to do so. The HCPOA is an excellent tool that maximizes a person's chances of avoiding court involvement. (For more information about HCPOA's, please see the "Alternatives to Guardianships and Conservatorships" section of this *Guide*.) A guardianship may still be necessary, however, if the named agent is unable or unwilling to act for the loved one. In other cases, where the agent could and would act under the HCPOA, the loved one may be uncooperative or antagonistic and may not allow the agent to assume any responsibility. In such a case, a guardianship may offer the only solution for care, treatment, and placement issues.

### **What does a guardian have to do?**

Basically, a guardian is responsible for the care, comfort, and maintenance of the ward. In making decisions for the ward, the guardian must consider the ward's wishes. The guardian must make sure the ward's living arrangements are the most appropriate and the least restrictive based on the ward's needs, abilities, and financial resources. The guardian can place the ward in an assisted living facility or skilled nursing facility if necessary. The guardian must make sure that the ward has appropriate and sufficient clothing. The guardian must also make sure the ward receives appropriate medical care, and the guardian has the authority to consent to medical care or other professional services. The guardian must report to the court annually about the ward's health, welfare, and status.

Usually, the guardian does not handle the ward's money. In some circumstances, a conservator may be appointed by the court to manage the ward's assets. If the guardian is authorized to do so and does receive any money on behalf of the ward, it must be used for the ward's care and support. The guardian should *not* use funds belonging to the ward for the benefit of the guardian or the guardian's family unless the charges are approved by the court.

### **How is a guardian appointed?**

Someone, often a family member, petitions the court for the appointment of a guardian. The court schedules a hearing on the incapacity of the proposed ward. An attorney is appointed to represent the proposed ward, and a court investigator is assigned to interview family members

and/or friends of the proposed ward and make a report to the court. A physician's report regarding capacity issues and the need for a guardianship is also necessary. At the hearing, the judge or commissioner hears testimony, considers the report of the physician, and appoints a guardian if appropriate.

### **What is a “mental health” guardianship?**

Under a regular guardianship, the guardian has the power to consent for the ward to receive psychological or other mental health care and treatment as long as that care and treatment is done on an outpatient basis and does not involve inpatient treatment at a mental health facility. In certain circumstances, inpatient mental health care and treatment may become necessary. In that event, the court must give specific authority to the guardian that allows the guardian to consent to inpatient mental health care and treatment for the ward. A mental health guardianship, therefore, is a guardianship that gives the guardian additional authority to consent for the ward to receive inpatient psychiatric and psychological care at a behavioral health facility when the ward needs it. The additional authority is only granted for a limited period of time up to one year. This authority can be requested when guardianship proceedings are first initiated, or it can be requested after a regular guardianship has been established. For a “mental health” guardianship to be established, a psychologist or psychiatrist must evaluate the proposed ward and make a report to the court.

For instance, when a loved one begins exhibiting combativeness and aggression, inpatient treatment may be necessary so that the ward's medications can be adjusted appropriately. Severe depression may also require hospitalization. Inpatient mental health care for seniors is often provided at a “geriatric psychiatric unit” of a hospital. Typically, a stay ranging from a few days to three or four weeks may be required to stabilize the patient. After the inpatient treatment, the person often returns to the previous residential care setting.

### **Guardianship – Review Questions**

- What things can a guardian decide for his or her ward?
- In what types of situations are guardians necessary when there is a Health Care Power of Attorney in place?
- What are the laws surrounding guardians and their access to the ward's money?
- Who appoints and approves a person to be a guardian?
- Under a regular guardianship, a guardian can make decisions about what types of psychological or mental health care and treatment?

## **C. Conservatorship:**

After reading this section you will be able to:

- Define conservator
- Discuss when a conservatorship is necessary
- Understand the responsibilities of a conservator
- Understand how a conservator is appointed
- Define different types of guardianship, including “mental health” guardianship

### **What is a conservator?**

A conservator is an individual appointed by the court to make financial decisions for someone else, who is called the “protected person”. The court can grant very broad powers to the conservator to handle all of the protected person’s assets, or the court can restrict the conservator’s powers as necessary under the circumstances.

### **When is a conservatorship necessary?**

A conservator may need to be appointed for persons who are unable to manage their financial affairs effectively due to mental or physical illness or disability or the chronic use of drugs or alcohol, etc., and who have property that will be used up without proper management. Sometimes a conservator is necessary where an agent under a power of attorney has not acted in the best interests of the person who appointed the agent. Family and friends should ask themselves the following questions:

- Can my loved one handle everyday money issues such as counting change, writing checks or balancing a checkbook?
- Could my loved one be easily persuaded by scam artists or others, including family members and friends, to give away money or other property?
- Does my loved one know what and where his/her assets are?

A full conservatorship is not always necessary. In certain circumstances authority to handle a single transaction or limited protective arrangements may be sufficient.

Example: Where all of a married protected person’s assets are titled in joint tenancy except one account, a single transaction authority may be appropriate to retitle the account so that the conservator spouse can manage it. Even single transaction authority, however, requires a petition to the court, and a hearing must be held.

Sometimes, a loved one has a durable Financial Power of Attorney (FPOA) in place, authorizing someone else to make financial and legal decisions when the loved one is not able to do so. The durable FPOA is an excellent tool that maximizes a person’s chances of avoiding court involvement. (See the “Alternatives to Guardianships and Conservatorships” section of this *Guide* for more information about durable Powers of Attorney.) A conservatorship may still be necessary, however, if the named agent is unable or unwilling to act for the loved one. In other cases, where the agent could and would act under the Financial Power of Attorney, the loved one may be uncooperative or antagonistic and may not allow the agent to assume any responsibility. Unfortunately, sometimes the agent named under a durable Power of Attorney does not act in the best interests of the loved one. In such cases, a conservatorship may offer the only solution for financial issues.

### **What does a conservator have to do?**

A conservator can authorize payment of debts and expenses and can also bring or defend legal actions on behalf of the protected person. The conservator must make an inventory of the protected person’s assets and indicate the fair market value of each asset. The conservator may



invest the funds of the estate, but must do so prudently. The conservator may acquire or dispose of property and may deal with insurance companies for the estate. The conservator must preserve and protect estate property and must pay income and property taxes. The conservator must also keep detailed records of all monies that come into or go out of the protected person's estate and then provide an annual accounting to the court, itemizing every expense and receipt. It is important to note that the conservator may *not* use funds belonging to the ward for the benefit of the conservator or the conservator's family unless the charges are approved by the court.

A conservator must qualify for a bond. The bond amount is usually set for the total amount of the protected person's assets plus one year's income. The amount of the bond may be reduced if the conservator agrees to restrict some of the assets. For instance, if the protected person had an investment account in addition to a checking and savings account, and if the checking and savings accounts had sufficient money to provide for at least one year of care and support for the protected person, then the conservator might decide to restrict the investment account. When an account is restricted, no one can withdraw or transfer funds from that account unless the court gives permission.

A conservator does not make any of the lifestyle, placement, or medical decisions for the protected person; those decisions are made either by close family members, an agent under a medical power of attorney or a court-appointed guardian.

### **How is a conservator appointed?**

An interested person (the "petitioner") petitions for the appointment of a conservator in the court of the county where the protected person resides or has property. The petitioner could be a family member or someone who would be affected if the protected person's assets are not managed appropriately. The petitioner could also be the protected person if that person desires protection for his/her assets.

The court schedules a hearing on the matter. An attorney is appointed to represent the proposed ward, and a court investigator is assigned to interview family members and/or friends of the proposed ward and make a report to the court. The court may also require a medical or psychological report from a medical expert. At the hearing, the judge or commissioner hears testimony, considers any medical report, and appoints a conservator if appropriate.

### **Conservatorship – Review Questions**

- Who appoints a conservator?
- In what types of questions should be asked when considering a conservatorship?
- When is a full conservatorship not necessary?
- What must a conservator qualify for? What is the bond amount usually equal to?

## **D. Medicare vs. Medicaid (ALTCS):**

After reading this section you will be able to:

- Discuss the major differences between Medicare and Medicaid (ALTCS)
- Understand the goal and concept of ALTCS
- Know how ALTCS services are managed and authorized
- Understand the medical and financial requirements of the ALTCS program

### **Medicare/Medicaid (ALTCS) Differences:**

People often confuse the Medicare program with the Medicaid program. There are major differences between these two separate and distinct programs.

Medicare is the federally-funded health insurance program designed to provide healthcare services primarily to individuals over the age of 65. Recent changes to the program have expanded benefits through Medicare managed plans. However, long-term nursing home benefits have never been part of either managed care or traditional Medicare plans.

**Options:** Your loved one is enrolled in traditional Medicare. What is available? In most cases, Medicare will cover the first 20 days in a skilled nursing facility. In rare circumstances, Medicare may cover the next 80 days of nursing home care, but with a deductible that is over \$100 per day. If your loved one is enrolled in a managed Medicare plan, days 21-100 are covered without a deductible, but only if your loved one meets strict qualification criteria. We strongly recommend a complete review of your health benefits so that you can be prepared and understand the qualifying factors to receive services. If your loved one receives treatment and recovers, he or she may again be eligible for additional Medicare skilled nursing benefits.

It is difficult to predict how many days of skilled nursing care Medicare will cover. From our experience at Jackson White Attorneys at Law, we have found that our clients rarely receive benefits that extend to the 100-day maximum. So, what happens when Medicare discontinues coverage, but your loved one still requires around-the-clock care? As stated above, the options available are either long-term care insurance, payment from one's own limited assets, or coverage through the Arizona Long Term Care System (ALTCS), Arizona's Medicaid program.

ALTCS is Arizona's federally and state funded health insurance program that provides benefits to those who meet strict qualification requirements. ALTCS is not an entitlement program and, therefore, not all who need care will qualify. This program is unique to Arizona. It is based on a Managed Care concept which enables the State to pay for a myriad of services in the home of the member, to keep costs down and keep the member in the lowest level of care possible. Many people are fearful that this program is only for people who need nursing home care. The goal of the ALTCS program is to keep the members at the lowest level of care possible. This effort reduces the costs to the State while allowing the members to reside in their own homes or other less institutional residential settings. Many people apply too late for ALTCS, thinking that it only covers nursing home care. Help in the home, whether respite care, housekeeping assistance, or a combination of different services may mean the difference between a caregiver

being able to care for the family member a little longer in the home and moving into an institutional setting.

Benefits which may be available under ALTCS include acute care services (doctors, hospitalization, prescriptions, lab work, x-rays, tests, and specialist treatments), nursing home care provided in a licensed nursing facility, residential or intensive care facilities, home and community based services (HCBS), which include home health nursing, rehabilitation, adult day care, personal and respite care, medical transportation, mental health services, homemaker services, attendant care, home health aids and home delivered meals. The services are managed and authorized via a case management program. Each member has a case manager assigned to them. This case manager, will assess the needs of the member quarterly, or more often if changes occur, and authorize services based on need. The services can change along with the needs of the member. There is no limit to the number of times you can move, change services or increase/decrease services. The case manager is the link to the system and works with the member and family to meet the physical, social and emotional needs of the member. Please review the glossary of terms at the end of this booklet for a complete explanation of the different benefits offered.

Unlike Medicare, which covers only skilled nursing services, ALTCS covers a continuum of healthcare services for which Medicare refuses to pay.

Example: Long-term stays in a nursing home that are necessitated by one's affliction with Alzheimer's or Parkinson's disease would not be covered by Medicare, even though the patient may need medical care on a daily basis. In contrast, the ALTCS program would pay for the custodial nursing home stay along with the attendant daily care for as long as necessary.

As with any government program, individuals must meet certain eligibility requirements before they can receive benefits. The ALTCS program requires the applicant to meet both **medical and financial** requirements. The criteria for these requirements are outlined below. The State of Arizona determines eligibility for ALTCS.

### **Medical Eligibility:**

The medical eligibility process is known as the Pre-Admission Screening process (referred to as a "PAS"). The PAS process includes an interview in the applicant's home by a PAS assessor from ALTCS who will gather information such as age, date of birth, living arrangements and physician information. Next, the PAS assessor will assess the needs of the applicant, such as need for assistance in activities of daily living, continence, sensory impairments, orientation and behavior. Based upon all this relevant medical information, the PAS assessor will make the medical qualification determination. The assessment is based on a numeric scoring tool. The more functionally impaired a person is the higher the score. A person with dementia (documented by a physician) needs to score 40 points or more to be medically eligible and the person without dementia needs to score at least 60 points. Some hints to help with the medical assessment are as follows:

1. Do not let the person who is applying for the program be alone during the interview process. It is a very difficult thing to tell a stranger that

you CANNOT accomplish certain ordinary tasks, let alone talk about very personal issues. But the scoring is based on what is said during the interview. If the applicant says that they do not have a continence issue, but in reality does, the score will not reflect the true limitations.

2. Always answer the medical questions as if it is your worse day. Just because the day of the interview, the applicant was able to transfer to the commode by themselves, but 90% of the time they can not, they need to answer the question true to the worst day.
3. Have medical paperwork back up any limitation that you may have. Have the medical records available during the interview to save time.

Medical eligibility is based on a person's risk of going into a nursing home.

Example: A person has a loving daughter taking care of the housekeeping and meals, the answers to the questions are that the individual applying is unable to do the housekeeping and meals. Questions need to be answered as if there were no daughter taking care of needs.

Typically, the discharge planner, social worker or other hospital healthcare staff with whom you have been working has a good idea of whether the applicant will medically qualify for ALTCS. The more difficult assignment will be to review and prepare appropriately for the financial requirements of the program.

### **General Eligibility Requirements:**

There are certain general criteria an applicant must meet before the financial assessment is made. The applicant must:

- Be under 18 or over 65, blind, disabled, parent of a dependent child, or pregnant
- Provide actual documentary evidence that applicant is a U. S. citizen or legal alien
- Be an Arizona resident
- Have a Social Security number
- Reside in a medical institution or approved home and community bases setting
- Be willing to assign rights to medical benefits
- Make an effort to secure potential primary benefits
- Be cooperative and provide verifications

The financial assessment will take into consideration both the income and the resources {assets} of the applicant. Remember that the application is based on the income/assets of the individual applying only--even if the applicant lives with a daughter, the only income and assets that the State will review are those of the applicant.

**Monthly Income Eligibility (such as Social Security, Pensions, Retirement):**

The limitations placed on income are dependent upon the marital status of the applicant. If the applicant is single, the maximum income cannot exceed \$1,869 per month. If both husband and wife are applying for benefits, the monthly income cannot exceed \$3,738. These limitations for both single and married applicants are effective for the year 2007 and are reviewed on an annual basis.

**Resource Eligibility (such as stocks, bonds, land, trusts):**

Again, the applicant's marital status plays a part in the limitations imposed upon resources when applying for ALTCS. A single applicant may have \$2,000 in countable resources; if both husband and wife are applying at the same time, the countable resources cannot exceed \$3,000. The key words are countable resources.

What are countable resources? ALTCS considers certain resources (assets) of the individual or family as exempt and does not include exempt resources when making the financial assessment. Exempt resources are distinguished from countable (non-exempt) resources. In general, the following are the primary exempt resources:

- A home with no greater than \$500,000 equity, or of any value if spouse, minor, blind, or disabled child lives in home The home must be the principal place of residence. The single nursing home resident may be required to show some "intent to return home" even if this never actually takes place
- One vehicle (Value limited to \$4,500 for a single individual)
- Burial plots
- Irrevocable prepaid funeral plans (The state allows only \$1,500 in cash if set aside for burial but an unlimited amount if prepaid to the funeral home and irrevocable.)
- Life insurance, if the face value is \$1,500 or less (If it exceeds \$1,500 in total face value, the cash value in this policy is countable.)
- A variety of other assets, depending upon the circumstances

All other resources are generally considered non-exempt and are countable for purposes of financial eligibility. These resources include all money and property that can be valued and converted into cash including, but not limited to:

- Cash, checking, and savings accounts
- Certificates of deposit
- U.S. savings bonds
- Retirement accounts including IRA, 401K, and TSA plans
- Nursing home accounts
- Pre-paid funeral contracts which can be cancelled
- Trusts
- Real estate other than the primary residence
- Second car

- Boats or recreational vehicles
- Stocks, bonds, or mutual funds
- Promissory notes

While the ALTCS rules are complicated, it is safe to say that a single person will qualify for ALTCS as long as he or she holds less than \$2,000 in countable resources and has less than \$1,869 per month of income and has not gifted or transferred any money or property.

### **Anti Impoverishment Laws – Assistance for the Well Spouse:**

The government recognizes that in instances where there is a well spouse; imposing strict limitations will cause the well spouse to become impoverished. In an effort to avoid this result, certain guidelines have been established to provide additional resources for the care and support of the well spouse. This additional allowance of resources is known as the Community Spouse Resource Deduction ("CSRD").

The CSRD allows the well spouse to keep one-half of the countable resources with a minimum deduction of \$20,328 and a maximum deduction of \$101,640.

Example: If a married couple has \$20,000 in countable resources, the amount of the deduction would be \$20,328 (minimum). If the couple has \$100,000 in countable resources, the deduction would be \$50,000. If the couple has \$200,000 in countable resources, the deduction would be \$101,640 (maximum). The minimum and maximum amounts provided here are effective for 2007 and are reviewed each year.

Once the exempt resources have been determined and a community spouse resource deduction has been applied, any remaining resources are subject to spend down.

### **Medicare vs. Medicaid (ALTCS) – Review Questions**

- What type of benefits have never been a part of either managed care or traditional Medicare plans?
- How many days in a skilled nursing home does Medicare cover?
- What type of concept is ALTCS based from?
- What is the goal of ALTCS?
- What services does ALTCS cover?
- What is the Case Manager's role in the ALTCS program?
- Please list the general requirements for eligibility in the ALTCS program.
- Medical eligibility for ALTCS is based on what?
- Monthly income cannot exceed what when applying for single (not married) ALTCS eligibility?
- The Community Spouse Resource Deduction allows the well spouse what?

## **Glossary:**

### **ALTCS**

Arizona's Medicaid program which is federally and state funded and administered by the Arizona Long Term Care System, a division of AHCCCS. This program will cover the entire cost of nursing home care and limited in-home care if certain medical and financial requirements are met.

### **Assisted Living (Non-Medical Senior Housing)**

General term for living arrangements in which some services (meals, laundry, medication reminders) are available to residents, but residents live independently within the assisted living complex. In most cases, assisted living residents pay a regular monthly rent, and then pay additional fees for the services they require. ALTCS covers this service in many situations. The facility should be asked if they have a contract with the ALTCS program.

### **Case Manager**

A social worker or healthcare professional, who evaluates, plans, locates, coordinates and monitors services with an older person and the family. Once on the ALTCS program, a Case Manager is assigned to the member to coordinate service. These professionals have access to your loved one's need and home situation and they coordinate and monitor the necessary care and services. They work closely with you and other family members, making it possible even for those who live far away to stay involved. ALTCS covers this service.

### **Capacity**

Ability to understand the nature of an act and the consequences and effects of chosen actions.

### **Centers for Medicare and Medicaid Services (CMS)**

The federal agency that runs Medicare and Medicaid, and Children's Health Insurance Program, and works to make sure the beneficiaries in these programs have access to high quality health care.

### **Community Spouse Resource Deduction (CSRD)**

The additional allowance of resources given to a well spouse. The CSRD allows the well spouse to keep one-half of the countable resources with a minimum deduction of \$20,328 and a maximum deduction of \$101,640.

### **Conservator**

Person appointed by the court in a legal proceeding to act as the legal representative of a person who is mentally or physically incapable of managing his or her financial affairs.

### **Durable Medical Equipment**

Medical equipment that is ordered by a doctor for home use. These items must be reusable, such as walkers, wheelchairs or hospital beds. This service is covered by ALTCS.

### **Financial Power of Attorney**

Allows a designated representative to make financial and legal decisions for a person.

### **Guardian**

Person appointed by court to make personal, placement and medical decisions for a person who is incapacitated.

### **Health Care Power of Attorney**

Allows a designated representative to make health care decisions for a person who is incapacitated.

### **Home and Community Based Services (HCBS)**

Most people want to remain at home as long as possible. A person who is ill or disabled and needs help may be able to get a variety of home services that might prevent one from having to move into a nursing home. Home and community based services usually covered by ALTCS include:

- Personal care
- Respite care
- Medical transportation
- Nursing care
- Home health aide
- Home modification
- Attendant care
- Adult day care
- Durable medical equipment

### **Living Will**

A document that makes known a person's wishes regarding medical treatments, usually for those at the end of life.

### **Medical Health Care Power of Attorney**

Allows a designated representative to make mental health care decisions for a person.

### **Medicare**

Federal program providing health care coverage/insurance for people over 65 years of age, certain younger people with disabilities and people with End-Stage Renal Disease (ESRD) (permanent kidney failure that must be treated with dialysis or a transplant). Part A covers inpatient care, skilled nursing facility, hospice and short-term healthcare. Part B covers doctors' services, outpatient hospital care and durable medical equipment. It does not provide for long-term care of the elderly except under limited conditions.

### **Pre-Admission Screening Process (PAS)**

The medical eligibility process for participation in the ALTCS program. The PAS assessor will make a medical qualification determination.

### **Surrogates**

An alternative decision maker for someone who cannot make or communicate health care treatment decisions.

### **Trust**

Used for the management of assets during a person's lifetime.