



Fundamentals of Dementia Care for Health Facility Personnel

Alzheimer's Association, Greater Indiana Chapter

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Funded by the Indiana State Department of Health

Co-sponsored by:

Indiana Association of Homes and Services for the Aging, Inc. (IAHSA)

Indiana Health Care Association (IHCA)

Hoosier Owners and Providers for the Elderly (HOPE)



Indiana State Department of Health

I am pleased to welcome you to the *Alzheimer's and Dementia Care Training Program*. The Indiana State Department of Health thanks you for your participation in this important program. It is our hope that you will gain a better understanding of Alzheimer's disease and related dementias and carry back to your health facility new ideas for best care practices.

The *Alzheimer's and Dementia Care Training Program* addresses a significant public health need being faced by many Indiana families. About 60% of all nursing home residents have dementia with 60% of dementias caused by Alzheimer's disease or Alzheimer's disease combined with vascular disease. There are currently an estimated 106,000 Indiana residents with Alzheimer's disease and that number is expected to grow considerably as the population ages. Approximately a third of those residents are cared for in long-term care facilities.

Caring for nursing home residents who have been diagnosed with Alzheimer's disease or dementia is often a challenge for health care providers. People with Alzheimer's disease or dementia have difficulty communicating, learning, thinking, and reasoning. Providing care to these residents requires patience, compassion, and an understanding of Alzheimer's and dementia disease processes. Providing this care on a daily basis can be difficult and trying for even the best caregivers.

To address these challenges, in 2004 the Indiana State Department of Health promulgated new rules requiring health facilities to provide training on Alzheimer's disease and dementia care to health facility personnel. To promote the implementation of the new rule and assist health facilities in the development of quality training programs, the Indiana State Department of Health funded this *Alzheimer's and Dementia Care Training Program*.

In developing the program, the Indiana State Department of Health sought the assistance of the Alzheimer's Association of Greater Indiana. The Alzheimer's Association is providing their significant expertise to develop, organize, administer, and present eight courses ranging from a basic course on the fundamentals of Alzheimer's disease and dementia to an advanced course on directing a dementia special care unit. The program is designed with the intent of reducing deficient practices at long term care facilities and improving the quality of life and care for residents with Alzheimer's disease and related dementias living in Indiana long term care facilities.

On behalf of the Indiana State Department of Health and the Alzheimer's Association of Greater Indiana, I thank you for choosing to participate in this program and I invite you to attend more of the *Alzheimer's and Dementia Care Training Program* courses offered during the coming year. I especially thank the staff of the Alzheimer's Association of Greater Indiana for their efforts in putting this program together. Thanks to their expertise and dedication, I am sure that you will come away with a better understanding of Alzheimer's disease and dementia. It is our hope that you will carry this information back to your facility and implement the best care practices suggested by this course. Indiana's senior citizens are a very special group that has made significant contributions to our society. Our senior citizens deserve the very best of care and I hope this program provides a forum for health care providers and experts to share ideas towards achieving the best of care for our senior citizens.

Terry Whitson
Assistant Commissioner
Health Care Regulatory Services
Indiana State Department of Health

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Fundamentals of Dementia Care for Health Facility Personnel



The Alzheimer's Association, founded in 1980, is the only national voluntary health organization dedicated both to research and providing education and support. With over 81 chapters nationwide, our vision is a world without Alzheimer's disease. Our mission is to eliminate Alzheimer's disease through the advancement of research and to enhance quality of care and support for individuals, their families and caregivers.

The Association strongly believes that education enhances the quality of care for those with Alzheimer's disease. By providing professional caregivers with the understanding, insight and tools necessary to provide the highest level of care throughout the person with Alzheimer's disease journey we are helping patient's maintain dignity and independence for as long as possible.

The *Alzheimer's and Dementia Care Training Program* has been designed as a "best practice". Experts in dementia care, locally and throughout the country, have contributed in the development of this training program. Their expertise, approaches, techniques and personal experiences are woven throughout the curriculum. Our hope is that each participant will gain a better understanding of the disease process, learn how to embrace and implement person centered care, assimilate new communication skills and learn how to work with the feelings behind the behaviors. In addition, the most commonly cited deficient practices in Indiana long-term care facilities are also addressed.

The Alzheimer's Association hopes that each participant of the *Alzheimer's and Dementia Care Training Program* will experience an increased sense of satisfaction and reward by putting into practice the techniques learned in the training program. Each caregiver has the opportunity to contribute to the creation of a nurturing environment that promotes the highest level of mental, emotional and physical capacity for those each caregiver serves.

In closing, we wish to thank the Indiana State Department of Health, Indiana Association of Homes and Services for the Aging, Inc. (IAHSA), Indiana Health Care Association (IHCA), Hoosier Owners and Providers for the Elderly (HOPE), our staff, volunteers and trainers for their support and assistance in the development and implementation of the program. Through this collaborative effort, we seek to improve the quality of care and quality of life for persons with Alzheimer's disease in the State of Indiana.

Heather Allen Hershberger
Executive Director
Alzheimer's Association of Greater Indiana

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Becky Armstead is a co-owner of an adult day care in Fort Wayne, Indiana. She previously has been a charge nurse in a dementia unit and an assisted living coordinator. Ms. Armstead has presented on dementia, challenging behaviors, and other topics related to dementia care.

Rosella Bennett, RN

Rosella Bennett is currently the Alzheimer's Care Director for a long-term care facility in Richmond, Indiana. She has been active in the Alzheimer's Association of Greater Indiana as part of the East Central advisory committee and through public policy efforts. Past positions include MDS Patient Coordinator, Charge Nurse, Director of Nursing, and Group Leader. She has presented on challenging behaviors, programming for dementia care units, and communication.

Susan Charlesworth, MSW

Ms. Charlesworth is a consultant in social services and activities for a company in Indianapolis, Indiana. She has presented on dementia care, resident rights, behavior management, MDS, activities, and social services. She holds a master of social work from Indiana University and a Bachelor of Science in education from Butler University. She is a member of the Indiana Society for Social Work Leadership in Health Care.

Shawn Fingerle, MS, MBA, LCSW

Shawn Fingerle is currently a professional healthcare representative in the long term care division of a pharmaceutical manufacturer. In previous positions, he has directed two psychiatric hospitals, been the administrator for home care services, and directed outpatient and diagnostic services. Mr. Fingerle has presented on topics such as treatment of depression and anxiety disorders, treatment of neuropathic pain, and general psychology courses. He is also on the Fort Wayne Advisory Committee for the Alzheimer's Association.

Debra Guy, AS

Debra Guy is a volunteer coordinator for a hospice company in Fort Wayne, Indiana. She has led a variety of trainings in the past, including end of life care, hospice, psychosocial and spiritual dynamics, culture/religion and grief, handling personal stress, communication, and physical and social aspects of the dying patient.

Marilyn Hartle, MSW, LCSW

Ms. Hartle is the co-owner of a consulting company in Indianapolis, Indiana. Ms. Hartle serves on the annual state Alzheimer's Education Conference Planning committee of the Alzheimer's Association, Greater Indiana Chapter. She is a Dementia Care Mapping (DCM) Evaluator, DCM Basic Course Trainer, and serves on the National Dementia Care Mapping Advisory Board. She is on the Education and Training Committee of the National Adult Day Services Association.

LaDonna Jensen, RN

Ms. Jensen is the a founding partner of a consulting company in Indianapolis, Indiana. She is an Advanced Dementia Care Mapper and Evaluator and serves on the National Dementia Care Mapping Advisory Board. She is one of 35 licensed international Dementia Care Mapping Basic Course trainers. She also trainers for the National Association of Adult Day Services and serves a consultant to the National Easter Seals Adult Day Services Program. Ms. Jensen currently serves as the chairperson of the Indiana Governor's Task Force on Alzheimer's.

Chip Koltash, MDiv, MSW, LCSW

Mr. Koltash is a social worker with a hospital in Fort Wayne, Indiana in the gero-psych department. In previous positions, he has also worked in home care/hospice, long term care, acute care, and outpatient psychotherapy. Currently on the Fort Wayne Advisory Board for the Alzheimer's Association, Greater Indiana Chapter, he has also provided professional and community education related to the care of persons affected by dementia.

Sharon Kennell, RN, C, BHA, CLNC

Sharon Kennell is the owner of a consulting company in Plainfield, Indiana. She is a legal and geriatric nurse consultant; she has previous experience as a LTC surveyor supervisor with the Indiana State Department of Health. She has presented on many topics, such as understanding dementia, behavioral symptoms, successful abuse prevention, and best practices for survey compliance on dementia units.

Carey Ann Mayermick, BSW

Carey Mayermick is a community liaison for a long term care facility in Indianapolis, Indiana. She has previously been a social service director, dementia care unit manager, and marketing and admissions director. Ms. Mayermick is a member of the Indiana Society for Social Work Leadership and the Indiana Continuity of Care Association.

Julie Priest-Young, MS, ACC

Julie Priest-Young is the owner and principle consultant of a social services/activities consulting company in Indiana. She has over 18 years of experience in long term care, has authored several policy and procedure manuals, and has spoken to several organizations throughout the state and mid-west.

Heather Schuck, BS

Heather Schuck is an activities and social services consultant for a long term care company. Heather has provided numerous trainings for the Alzheimer's Association, Greater Indiana Chapter, including behavior management, activities, environmental design, family dynamics, and communication strategies. Ms. Schuck is also a support group leader.

Stephanie Stilabower, LPN

Stephanie Stilabower is a co-owner of an adult day care in Fort Wayne, Indiana. She has been a director of a memory care unit and worked as an LPN for 25 years. Ms. Stilabower has presented on dementia, staffing, and other dementia topics.

Amy Stock, MSW, LCSW

Ms. Stock is a medical social worker for a home health and hospice company in Fort Wayne, Indiana. She has 12 years of experience assisting clients who are seeking help through various medical settings. Ms. Stock is a member of the National Association of Social Workers.

About the Author

Kate Nicholson, MA

Kate Nicholson is the Education and Training Coordinator for the Alzheimer's Association of Greater Indiana. Previously, she has held positions in service agencies developing educational programs and services. She holds a Master of Art in Adult and Community Education, Bachelor of Science in Public Relations, and an Associates of Science in Journalism. Ms. Nicholson is a member of the American Association of Adult and Continuing Education.

Agenda

7:30-8:00 am	Registration and Pre-Test
8:00-8:15 am	Opening Remarks
8:15-9:00 am	Module 1: Understanding Memory Loss
9:00-10:15 am	Module 2: Person Centered Care
10:15-10:30 am	Break
10:30-11:30 am	Module 3: Communication Strategies
11:30-12:30 pm	Lunch
12:30-1:45 pm	Module 4: Understanding Behaviors
1:45-2:00 pm	Break
2:00-3:00 pm	Module 5: Activities of Daily Living
3:00-3:45 pm	Module 6 Families
3:45-4:00 pm	Summing up, Post-test, and Evaluation

Perf

F-Tags Used in This Manual

F-Tag Number	Title	Description	Module
154	Right to be informed.	The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including, but not limited to, his or her medical condition.	3
163	Be fully informed.	(Refer to 154. This is from Part II and III of 163): Part II: Be fully informed in advance about care and treatment and of any changes that may affect the resident's well-being. Part III: Unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State, participate in planning care and treatment or changes in care and treatment.	2
164	Privacy and confidentiality	The resident has a right to personal privacy and confidentiality of his or her personal and clinical records. Part 1: Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident.	5
221-222	Resident behavior and facility practices.	A) Restraints. The resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms.	1 4
223	Abuse.	The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.	2 3 4 5
224-226	Staff treatment of residents.	The facility must develop and implement written policies and procedures that prohibit mistreatment, neglect, and abuse of residents and misappropriation of resident property.	2 4 5 6

F-Tag Number	Title	Description	Module
225	Potential employees.	<ul style="list-style-type: none"> (1) Not employ individuals who have been <ul style="list-style-type: none"> a. Found guilty of abusing, neglecting, or mistreating residents by a court of law; or b. Have had a finding entered into the State nurse aide registry concerning abuse, neglect, mistreatment of residents or misappropriation of their property; and (2) Report any knowledge it has of actions by a court of law against an employee, which would indicate unfitness for service as a nurse aide or other facility staff to the State nurse aide registry or licensing authorities. (3) The facility must ensure that all alleged violations involving mistreatment, neglect, or abuse including injuries of unknown source and misappropriation of resident property are reported immediately to the administrator of the facility and to other officials in accordance with State law through established procedures (including to the State survey and certification agency). (4) The facility must have evidence that all alleged violations are thoroughly investigated, and must prevent further potential abuse while the investigation is in progress. (5) The results of all investigations must be reported to the administrator or his designated representative and to other officials in accordance with State law (including to the State survey and certification agency) within 5 working days of the incident, and if the alleged violation is verified appropriate corrective action must be taken. 	2
240	Quality of life.	A facility must care for its residents in a manner and in an environment that promotes maintenance of enhancement of each resident's quality of life.	2 5
241	Dignity.	The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.	2 5

F-Tag Number	Title	Description	Module
242	Self-determination and participation.	<p>The resident has a right to</p> <ol style="list-style-type: none"> (1) Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care; (2) Interact with members of the community both inside and outside the facility; and (3) Make choices about aspects of his or her life in the facility that are significant to the resident 	2 5
243-244	Participation in resident and family groups.	<ol style="list-style-type: none"> (1) The resident has the right to organize and participate in resident groups in the facility; (2) A resident's family has the right to meet in the facility with the families of other residents in the facility; (3) The facility must provide a resident or family group, if one exists, with private space; (4) Staff or visitors may attend meetings at the group's invitation (5) The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings; (6) When a resident or family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility. 	6
246	Accommodation of needs.	A resident has the right to reside and receive services in the facility with reasonable accommodations of individual needs and preferences, except when the health or safety of the individual or other residents would be endangered.	2 5

F-Tag Number	Title	Description	Module
280	Care plans.	<p>A comprehensive care plan must be</p> <ul style="list-style-type: none"> (i) Developed within 7 days after the completion of the comprehensive assessment; (ii) Prepared by an interdisciplinary team that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs, and, to the extent practicable, the participation of the resident, the resident's family or the resident's legal representative; and periodically revised by a team of qualified persons after each assessment. 	6
285	Preadmission screening.	Preadmission screening for mentally ill individuals and individuals with mental retardation.	1
309	Quality of care.	Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.	2 5
310	Activities of daily living.	<p>Based on the comprehensive assessment of a resident, the facility must ensure that</p> <ul style="list-style-type: none"> (1) A resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that diminution was unavoidable. This includes the resident's ability to— <ul style="list-style-type: none"> • Bathe, dress, and groom; • Transfer and ambulate; • Toilet; • Eat; and • Use speech, language, or other functional communication systems. 	5
316	Incontinence	A resident who is incontinent of bladder receives appropriate treatment and services to prevent urinary tract infections and to restore as much normal bladder function as possible.	5

F-Tag Number	Title	Description	Module
319	Mental and psychosocial adjustments.	A resident who displays mental or psychosocial adjustment difficulty receives appropriate treatment and services to correct the assessed problem.	1 2
320	Mental and psychosocial adjustments.	A resident whose assessment did not reveal a mental or psychosocial adjustment difficulty does not display a pattern of decreased social interaction and/or increased withdrawn, angry, or depressive behaviors, unless the resident's clinical condition demonstrates that such a pattern is unavoidable.	1
323-324	Accidents	The facility must ensure that <ul style="list-style-type: none"> (1) The resident environment remains as free of accident hazards as is possible; (2) Each resident receives adequate supervision and assistance devices to prevent accidents. 	5

F-Tag Number	Title	Description	Module
329	Unnecessary drugs.	<p>Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used</p> <ul style="list-style-type: none"> (i) in excessive dose (including duplicate therapy); or (ii) for excessive duration; or (iii) without adequate monitoring; or (iv) without adequate indications for its use; or (v) in the presence of adverse consequences which indicate the dose should be reduced or discontinued; or (vi) any combination of the reasons above. 	1
497	Regular in-service education.	<p>The facility must complete a performance review of every nurse aide at least once every 12 months, and must provide regular in-service education based on the outcomes of these reviews. The in-service training must—</p> <ul style="list-style-type: none"> (i) Be sufficient to ensure the continuing competence of nurse aides, but, must be no less than 12 hours per year; (ii) Address areas of weakness as determined in nurse aides' performance reviews and may address the special needs of residents as determined by the facility staff; and (iii) For nurse aides providing services to individuals with cognitive impairments, also address the care of cognitively impaired. 	2
498	Proficiency of nurse aids.	<p>The facility must ensure that nurse aides are able to demonstrate competency in skills and techniques necessary to care for residents' needs, as identified through resident assessments, and described in the plan of care.</p>	1

Tab



Understanding Memory Loss

Objectives:

- **Define dementia and Alzheimer's disease**
- **Understand the stages of the disease and expectations, including behaviors**
- **Understand current medications and treatments**

Overview of Dementia and Alzheimer's Disease

What is Dementia?

Dementia is not a disease, but a disease process. It is an umbrella term that refers to a group of symptoms, such as:

- Progressive decline in cognitive function
- Intellectual functions such as thinking, remembering, and reasoning are altered
- Severe enough to affect everyday life
- A person must have memory loss and loss in cognitive function

Over 170 illnesses cause **irreversible** dementia, including HIV-AIDs, vascular dementia, lewy-body disease, Parkinson's disease, Huntington's disease, and Alzheimer's disease.

There are some forms of **reversible**, or treatable forms of dementia, such as thyroid disorders, drug interactions, dehydration, and depression.



F-Tags

f498:

proficiency of nurse aids.

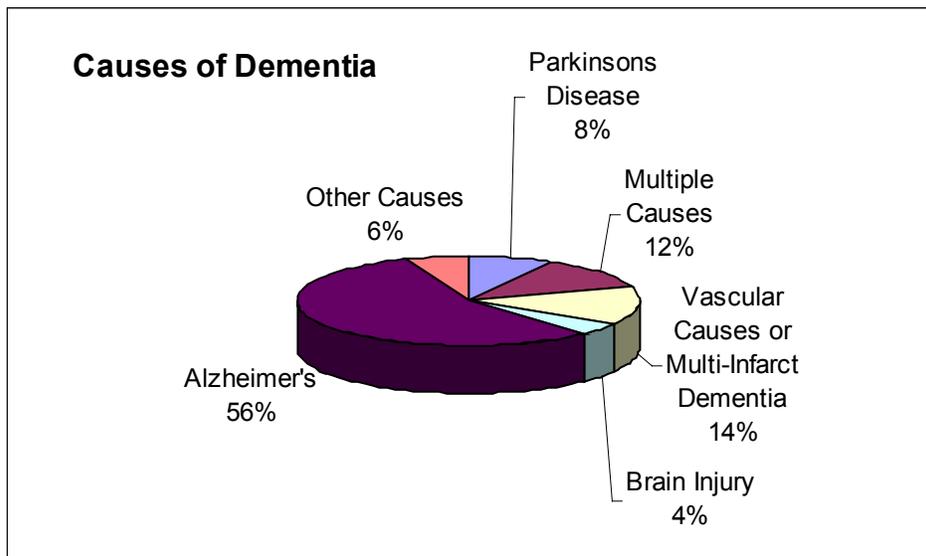
the unlearning

i would give it all
that i have and have not
to bring them all back
all the memories forgot
a lifetime of thoughts
that it is to be self
come tumbling down
down like books from a shelf
i lost a few things
it's so simple at first
walked the slow incline
of the alzheimer's curse
the beauty of youth
with the aging comes grace
look at reflection
not to recognize face
in a deepening fog
i shall wander for years
as the time slips by
i will lose my fears
in the end i forget
how to swallow or breathe
my unlearning is done
in the quiet i leave...
— by jack beavers

did you know?

the youngest documented case of alzheimer's disease was a man who was 19 years of age.

Other Dementias



Some of the other diseases that cause dementia are:

Creutzfeldt-Jakob disease (CJD) – a rare, fatal brain disease caused by infection.

Symptoms are failing memory, changes in behavior and lack of muscular coordination. CJD progresses rapidly, usually causing death within a year. No treatment is currently available.

Multi-infarct dementia (MID) – also known as vascular dementia, results from brain damage caused by multiple strokes (infarcts) within the brain. Symptoms can include disorientation, confusion and behavioral changes. MID is neither reversible nor curable, but treatment of underlying conditions (e.g., high blood pressure) may halt progression.

Normal pressure hydrocephalus (NPH) – a rare disease caused by an obstruction in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss and incontinence. NPH may be related to a history of meningitis, encephalitis, or brain injury, and is often correctable with surgery.

Pick's disease – a rare brain disease that closely resembles Alzheimer's, with personality changes and disorientation that may precede memory loss. As with Alzheimer's disease, diagnosis is difficult and can only be confirmed by autopsy.

Parkinson's disease – a disease affecting control of muscle activity, resulting in tremors, stiffness and speech impediment. In late stages, dementia can occur, including Alzheimer's disease. Parkinson drugs can improve steadiness and control but have no effect on mental deterioration.

Lewy body disease – a disease, recognized only in recent years, in which the symptoms are a combination of Alzheimer's disease and Parkinson's disease. Usually, dementia symptoms are initially present followed by the abnormal movements associated with Parkinson's. There is no treatment currently available.

Huntington's disease – a hereditary disorder characterized by irregular movements of the limbs and facial muscles, a decline in thinking ability, and personality changes. In contrast to Alzheimer's, Huntington's can be positively diagnosed and its movement disorders and psychiatric symptoms controlled with drugs. The progressive nature of the disease cannot be stopped.

Depression – a psychiatric condition marked by sadness, inactivity, difficulty with thinking and concentration, feelings of hopelessness, and, in some cases, suicidal tendencies. Many severely depressed persons also display symptoms of memory loss. Depression can often be reversed with treatment.

**alois alzheimer first discovered
alzheimer's disease in 1906.**

**for more information on
alzheimer's disease, call (800)
272-3900 or visit www.alz.org.**

DEMENTIA, DELIRIUM & DEPRESSION

The * areas identify hallmark signs of delirium	Delirium	Dementia	Depression
Attention	difficulty sustaining and shifting*	easily distracted	no change but may have a lack of interest
Level of Consciousness	decreased*; stupor*	no change	no change
Mood	no change	possible depression and/or anxiety	possible depression and/or anxiety
Onset	rapid or over several weeks	gradual	usually abrupt
Course	fluctuates*	progressive decline	rapid progression
Thinking	disorganized; delayed	impaired distraction and judgement; possible aphasia, agnosia and apraxia	negative; delayed
Memory	short term usually present	short term memory declines before long term memory; difficulty learning	complaints of memory deficits worse than actual deficits
Perceptual Changes	illusions; visual* and tactile hallucinations	possible hallucinations	none
Personality	no changes	altered or accentuated premorbid personality	may be irritable
Sleep / Wake Cycle	disturbed*	no change but may become irritable when tired and needing a nap	disturbed sleep; early morning awakening
Psychomotor Activity	increased; picking at sheets	Pacing, restless when needs not met	decreased

Alzheimer's Disease Explained

Alzheimer's disease (pronounced *AHLZ-hi-merz*) is a disorder that destroys cells in the brain. The disease is the leading cause of dementia, a condition that involves gradual memory loss, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impairment of judgment, and personality changes. As the disease progresses, people with Alzheimer's become unable to care for themselves. The loss of brain cells eventually leads to the failure of other systems in the body. The rate of progression of Alzheimer's varies from person to person. The time from the onset of symptoms until death ranges from 3 to 20 years. The average duration is about 8 years.

Alzheimer's disease is a progressive, ultimately fatal, disorder in which certain types of nerve cells in particular areas of the brain degenerate and die for unknown reasons.

Studies have shown that the greatest known risk for developing Alzheimer's is increasing age. As many as 10 percent of people 65 years of age and older have Alzheimer's, and nearly 50 percent of people 85 and older have the disease. A family history of the disease is another known risk. Having a parent or sibling with the disease increases an individual's chances of developing Alzheimer's.

Scientists have identified three genes that cause rare, inherited forms of the disease that tend to occur before age 65. Investigations of these genes have provided important clues about the biology of Alzheimer's. Researchers have also identified one gene that raises the risk of the more common form of Alzheimer's that affects older people.

Dr. Alois Alzheimer, a German physician, first described the disease in 1906. He observed in the autopsy of a woman with dementia two kinds of abnormal structures in the brain that are now recognized as hallmarks of Alzheimer's disease—amyloid **plaques** and neurofibrillary **tangles**.

**the normal adult forgets,
remembers that she forgot,
and later may remember
what she forgot. an
alzheimer's patient forgets,
forgets that she has
forgotten, and couldn't care
less five minutes later.
-dan blazer, m.d.**

**our value lies in what we are
and what we have been, not in
our ability to recite the recent
past.**

**— homer, a man with alzheimer's
disease**

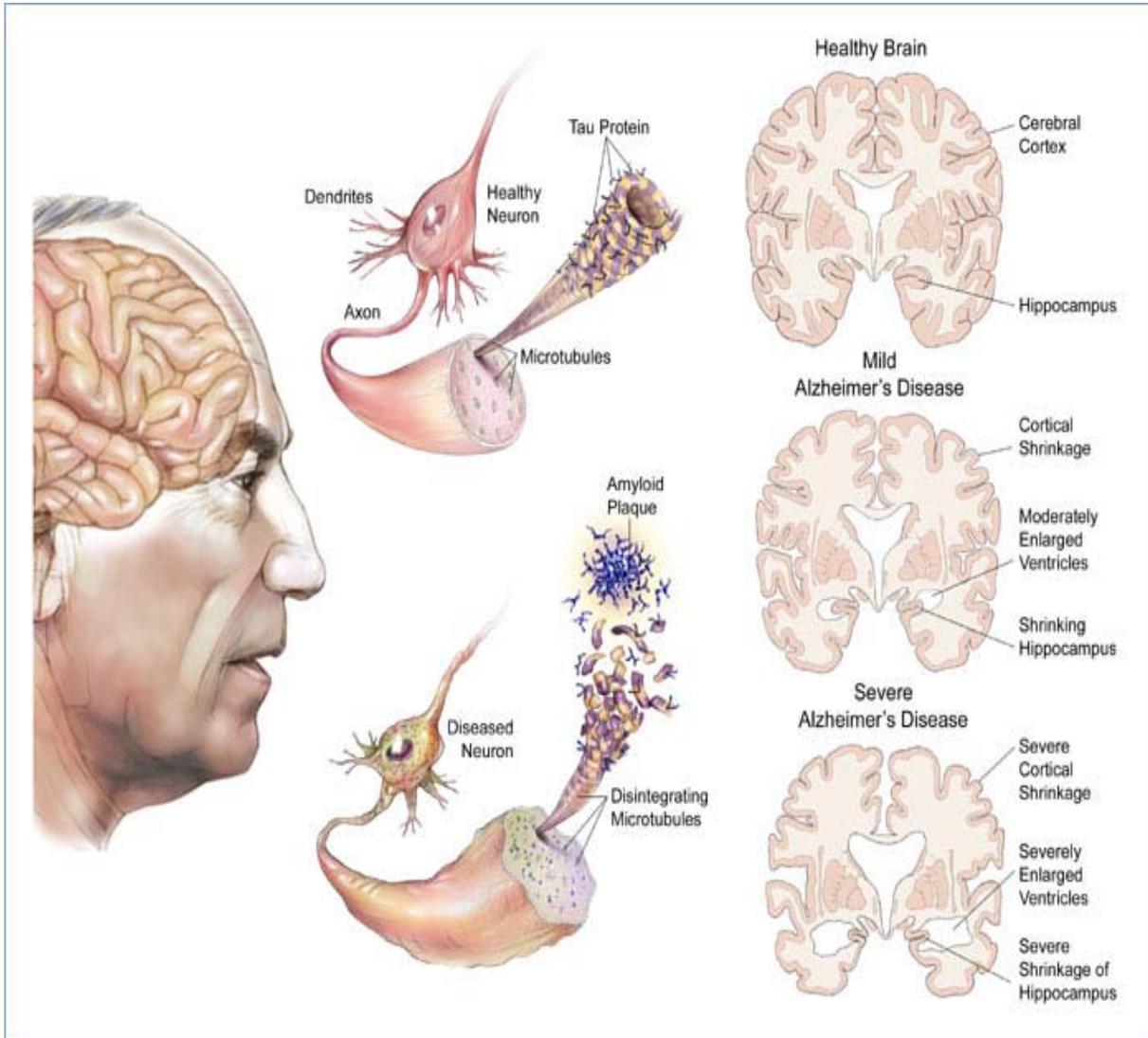
Since then, researchers have learned much about how these structures form, but they do not know exactly what role each structure plays in the loss of brain cells.

One of the hallmarks of Alzheimer's disease is the accumulation of amyloid plaques *between* nerve cells (neurons) in the brain. Amyloid is a general term for protein fragments that the body produces normally. Beta-amyloid is a fragment of a protein that is snipped from another protein called amyloid precursor protein (APP). In a healthy brain, these protein fragments would be broken down and eliminated. In Alzheimer's disease, the fragments accumulate to form hard, insoluble plaques.

Neurofibrillary tangles consist of insoluble twisted fibers that are found *inside* of the brain's cells. They primarily consist of a protein called tau, which forms part of a structure called a microtubule. The microtubule helps transport nutrients and other important substances from one part of the nerve cell to another (the axon is the long threadlike extension that conducts nerve impulses *away* from the body of a nerve cell, and dendrites are any of the short branched threadlike extensions that conduct nerve impulses *towards* the nerve cell body).

There is an overall shrinkage of brain tissue as Alzheimer's disease progresses. In addition, the ventricles, or chambers within the brain that contain cerebrospinal fluid, are noticeably enlarged. In the early stages of Alzheimer's disease, short-term memory begins to decline when the cells in the hippocampus, which is part of the limbic system, degenerate. Neurotransmitters decrease, which are the chemicals that send messages from cell to cell. The plaques interfere with the communication process. The ability to perform routine tasks also declines. As Alzheimer's disease spreads through the cerebral cortex (the outer layer of the brain), judgment declines, emotional outbursts may occur and language is impaired. Progression of the disease leads to the death of more nerve cells and subsequent behavior changes, such as wandering and agitation. The ability to recognize faces and to communicate is completely lost in the final stages. Patients lose bowel and bladder control, and eventually need constant care.

Brain and Nerve Cells Change with Alzheimer's Disease



Brain Scans

Brain with Alzheimer's

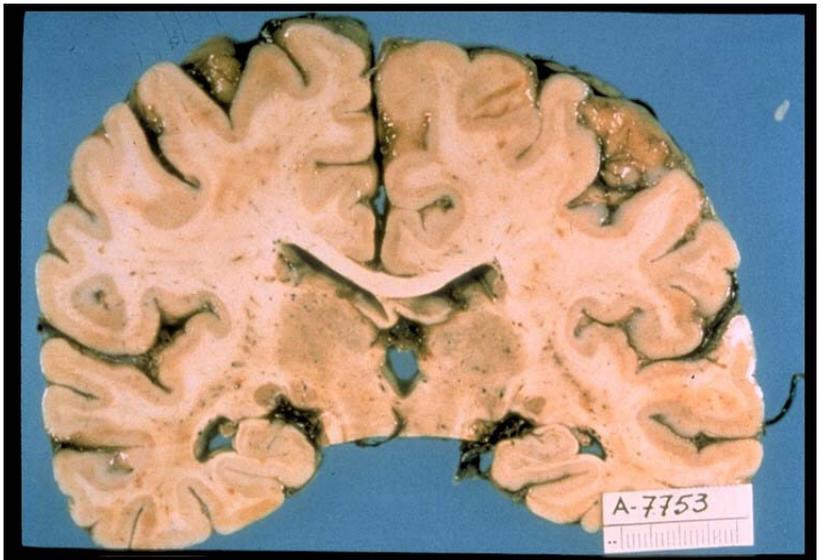


joe: sam, you know the worst thing about growing old?

sam: no, what's that?

joe: what's what?

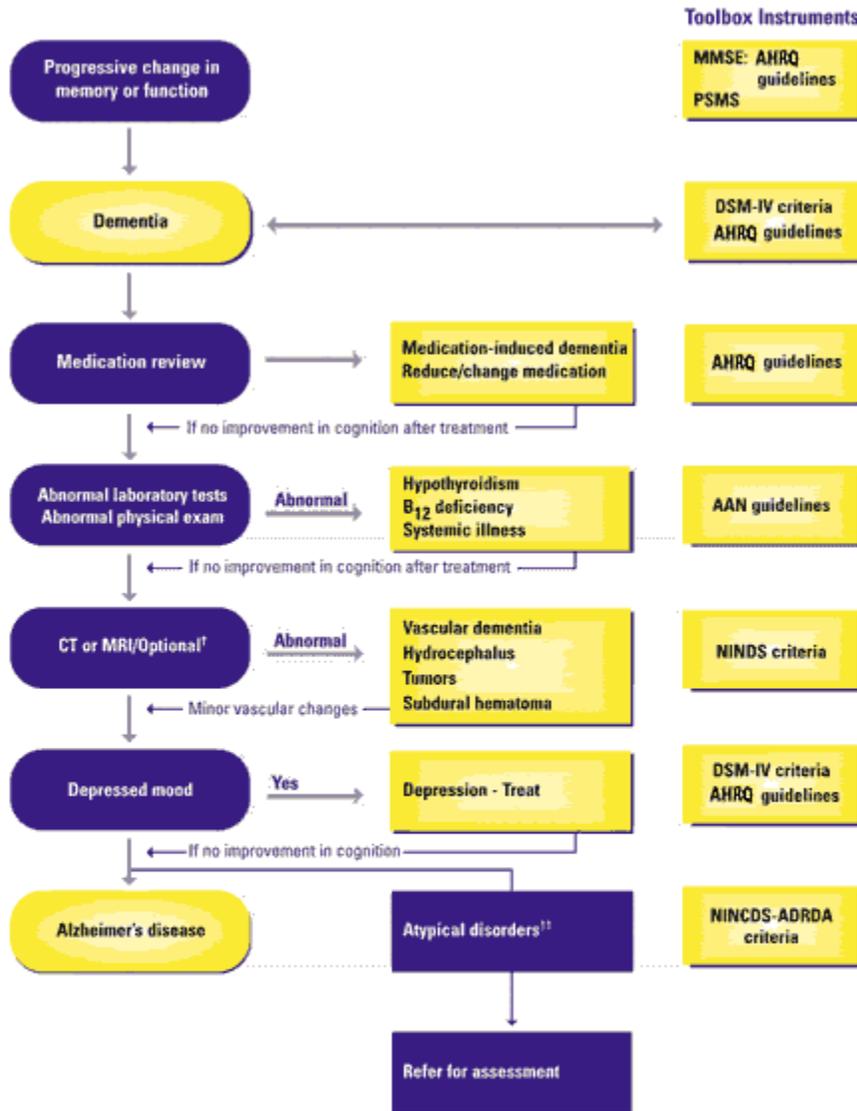
Brain without Alzheimer's



Diagnosing Alzheimer's Disease

The actual diagnostic workup involves several steps — an initial evaluation including a medical history, a mental status evaluation, a clinical examination, and laboratory tests — as outlined in the *Differential Diagnosis of AD Algorithm* appearing below.

Differential Diagnosis in AD Algorithm*



* Developed and endorsed by the *TriAD* Advisory Board. ©1996 Pfizer Inc and Eisai Inc., with special thanks to J. L. Cummings. Algorithm reprinted from *TriAD, Three for the Management of Alzheimer's Disease*, with permission.

† It is required in patients with focal signs, rapid progression, and headache.

†† This category will contain rare dementias (e.g., frontotemporal degenerations, Jakob-Creutzfeldt disease, Parkinson's disease [and other movement disorders that present with dementias]) that should be considered when unusual clinical features are present or a rapidly progressive course is noted.

it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another.

Stages and Expectations

Experts have documented common patterns of symptom progression that occur in many individuals with Alzheimer's disease and developed several methods of "staging" based on these patterns. Progression of symptoms corresponds in a general way to the underlying nerve cell degeneration that takes place in Alzheimer's disease. Nerve cell damage typically begins with cells involved in learning and memory and gradually spreads to cells that control every aspect of thinking, judgment, and behavior. The damage eventually affects cells that control and coordinate movement.

Staging systems provide useful frames of reference for understanding how the disease may unfold and for making future plans. ***But it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another.*** Not everyone will experience every symptom and symptoms may occur at different times in different individuals. People with Alzheimer's live an average of 8 years after diagnosis, but may survive anywhere from 3 to 20 years.

The framework of this is the Global Deterioration Scale, a system that outlines key symptoms characterizing seven stages ranging from unimpaired function to very severe cognitive decline.

Within this framework, we have noted which Global Deterioration Scale stages correspond to the widely used concepts of mild, moderate, moderately severe, and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, mid-stage, and late-stage categories.

Stage 1:	No cognitive impairment
	Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.
Stage 2:	Very mild cognitive decline
	Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses, or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family, or co-workers.
Stage 3:	Mild cognitive decline
	Early-stage Alzheimer's can be diagnosed in some, but not in all, individuals with these symptoms:
	<ul style="list-style-type: none"> • Friends, family, or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include: • Word- or name-finding problems noticeable to family or close associates • Decreased ability to remember names when introduced to new people • Performance issues in social or work settings noticeable to family, friends, or co-workers • Reading a passage and retaining little material • Losing or misplacing a valuable object • Decline in ability to plan or organize
Stage 4:	Moderate cognitive decline (Mild or early-stage Alzheimer's disease)
	At this stage, a careful medical interview detects clear-cut deficiencies in the following areas: <ul style="list-style-type: none"> • Decreased knowledge of recent occasions or current events • Impaired ability to perform challenging mental arithmetic-for example, to count backward from 100 by 7s • Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances • Reduced memory of personal history • The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations
Stage 5:	Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)

	<p>Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:</p> <ul style="list-style-type: none"> • Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated • Become confused about where they are or about the date, day of the week, or season • Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s • Need help choosing proper clothing for the season or the occasion • Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children • Usually require no assistance with eating or using the toilet
Stage 6:	<p>Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)</p>
	<p>Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with customary daily activities. At this stage, individuals may:</p> <ul style="list-style-type: none"> • Lose most awareness of recent experiences and events as well as of their surroundings • Recollect their personal history imperfectly, although they generally recall their own name • Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces • Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet • Experience disruption of their normal sleep/waking cycle • Need help with handling details of toileting (flushing toilet, wiping, and disposing of tissue properly) • Have increasing episodes of urinary or fecal incontinence • Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things

	<p>that are not really there; or compulsive, repetitive behaviors such as hand-wringing or tissue shredding</p> <ul style="list-style-type: none"> • Tend to wander and become lost
Stage 7:	Very severe cognitive decline (Severe or late-stage Alzheimer's disease)
	<p>This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.</p> <ul style="list-style-type: none"> • Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered • Individuals need help with eating and toileting and there is general incontinence of urine • Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.



F-Tags

f222:

chemical restraints

f329:

unnecessary drugs

Medications

Key elements of disease management include timely diagnosis and effective use of available therapies to manage cognitive and behavioral symptoms. Other important considerations include identifying co-morbid conditions and monitoring individuals for adequate nutrition, hydration, and pain management as well as signs of abuse.

Drugs currently approved specifically to treat Alzheimer symptoms all act chiefly by inhibiting acetylcholinesterase, the main enzyme that breaks down acetylcholine. For about 50 percent of the individuals who take them, these drugs offer a modest, temporary delay in worsening of cognitive symptoms. But cholinesterase inhibitors do not stop underlying neurodegeneration, and the disease inevitably progresses.

Today, new diagnostic tools and criteria make it possible for all physicians (primary care as well as specialists) to make a positive clinical diagnosis of probable Alzheimer's with an accuracy of approximately 90 percent. Recognizing symptoms early and accurately diagnosing a patient with Alzheimer's is important. Although the onset of Alzheimer's disease cannot yet be stopped or reversed, an early diagnosis gives patients a greater chance of benefiting from existing treatments and allows them and their families more time to plan for the future.

The U.S. Food and Drug Administration (FDA) has approved two classes of drugs to treat cognitive symptoms of Alzheimer's disease: cholinesterase inhibitors and NMDA receptor antagonists. Vitamin E supplements are frequently prescribed and have become a part of a standard treatment regimen for most people with Alzheimer's.

Cholinesterase Inhibitors

The first FDA-approved Alzheimer medications were cholinesterase inhibitors. Three of these medications are commonly prescribed—donepezil (Aricept®), approved in 1996, rivastigmine (Exelon®), approved in 2000, and galantamine (Reminyl®), approved in 2001. Tacrine (Cognex®), the first drug in this class, was approved in 1993 but is rarely prescribed today because of associated side effects, including possible liver damage.

Cholinesterase inhibitors are designed to enhance memory and other cognitive functions by influencing certain chemical activities in the brain. Acetylcholine is a chemical messenger in the brain that scientists believe is important for the function of brain cells involved in memory, thought, and judgment. Acetylcholine is released by one brain cell to transmit a message to another. Once a message is received, various enzymes, including one called acetylcholinesterase, break down the chemical messenger for reuse.

In the Alzheimer-afflicted brain, the cells that use acetylcholine are damaged or destroyed, resulting in lower levels of the chemical messenger. A cholinesterase inhibitor is designed to stop the activity of acetylcholinesterase, thereby slowing the breakdown of acetylcholine. By maintaining levels of acetylcholine, the drug may help compensate for the loss of functioning brain cells.

Galantamine also appears to stimulate the release of acetylcholine and to strengthen the way that certain receptors on message-receiving nerve cells respond to it.

How are cholinesterase inhibitors used?

Donepezil (Aricept®) is a tablet and can be administered once daily. Generally, the initial

cholinesterase inhibitors are designed to enhance memory and other cognitive functions by influencing certain chemical activities in the brain.

it is strongly recommended that a physician who is comfortable and experienced in using these medications monitor patients treated with any of these compounds and that the recommended guidelines be strictly observed.

dose is 5 mg a day(usually given at night). After four to six weeks, if it is well tolerated, the dose is often increased to the therapeutic goal of 10 mg a day.

Rivastigmine (Exelon®) is available as a capsule or as a liquid. The dosage is gradually increased to minimize side effects. Usually the medication is started at 1.5 mg daily. After two weeks the dosage is increased to 1.5 mg twice a day. The therapeutic goal is to increase the dosage gradually every two weeks to reach 6 to 12 mg a day. There is a greater frequency of side effects at these higher doses; however, taking drugs with meals may be helpful in reducing the occurrence of side effects.

Galantamine (Reminyl®) became available in pharmacies in May 2001. It is supplied in the form of tablets in strengths of 4, 8, and 12 milligrams.

What are the side effects of cholinesterase inhibitors?

Generally, donepezil is well tolerated. Because experience with rivastigmine and galantamine is limited, it is unknown how well these drugs will be tolerated in the general population. Symptoms such as nausea, vomiting, loss of appetite, and increased frequency of bowel movements might be expected with any cholinesterase inhibitor. It is strongly recommended that a physician who is comfortable and experienced in using these medications monitor patients treated with any of these compounds and that the recommended guidelines be strictly observed. There is no evidence or reason to believe that combining the drugs would be any more beneficial than taking either one alone, and it is likely that combining the drugs would result in greater side effects.

Memantine

Memantine was approved in October 2003 by the FDA for treatment of moderate to severe Alzheimer's disease. Forest Laboratories Inc., memantine's U.S. developer, will market the drug under the trade name Namenda®. Forest anticipates that memantine will be available in U.S. pharmacies by early 2004.

Memantine is classified as an *uncompetitive low-to-moderate affinity N-methyl-D-aspartate (NMDA) receptor antagonist*, the first Alzheimer drug of this type approved in the United States. It appears to work by regulating the activity of glutamate, one of the brain's specialized messenger chemicals involved in information processing, storage, and retrieval. Glutamate plays an essential role in learning and memory by triggering NMDA receptors to allow a controlled amount of calcium to flow into a nerve cell, creating the chemical environment required for information storage.

Excess glutamate, overstimulates NMDA receptors to allow too much calcium into nerve cells, leading to disruption and death of cells. Memantine may protect cells against excess glutamate by partially blocking NMDA receptors.

Memantine's action differs from the mechanism of the cholinesterase inhibitors that were previously approved in the United States for treatment of Alzheimer symptoms. Cholinesterase inhibitors temporarily boost levels of acetylcholine, another messenger chemical that becomes deficient in the Alzheimer brain.

It is hoped that this drug will help maintain personal care functions and assist in behavior management longer.

it appears to work by regulating the activity of glutamate, one of the brain's specialized messenger chemicals involved in information processing, storage, and retrieval.

memantine is often paired with a cholinesterase inhibitor.

notes

Tab



Person Centered Care

Objectives:

- **Understand person centered care and its characteristics**
- **Identify strategies for implementing person centered care**
- **Find ways to take care of the professional caregiver**

Take A Walk in Someone Else's Shoes!

Take a walk as someone with dementia. How does it feel? Answer the following questions.

How does it feel to be the resident?

How do you think the world sees you?

How do you want to be treated?

What can make you....

Sad?

Happy?

Angry?

Frustrated?

Involved?

now and then
she use to hug me and call me
"sweetie,"
that was then, and this is now,
she calls me "you" and gives me no
sign of recognition,
this is now and that was then,
she use to play house and dolls with
me,
that was then and this is now,
she cleans and cleans and makes me
clean too,
this is now and that was then,
she use to have decent conversations
with me,
that was then and this is now,
she babbles on and on about things
we don't know about,
this is now and that was then,
she use to know who i am,
that was then and this is now,
she doesn't even know that i am
related to her,
this is now and that was then,
i still love my grandmother very
much,
that was then and this is now. i hate
this awful disease that puts my
grandmother through no pain but
me and my family through torture,

this is now and that was then.

— *by ashley griffis, age 13, about her
grandmother*

Person Centered Care

Person centered care is truly putting the person first. Consider all needs, not just medical or physical.

Personal definition of person centered care:

The Philosophy of Person Centered Care

1. Behaviors are a desire for communication on the part of the person with dementia and an opportunity to share.
2. We must maintain and uphold the value of the person regardless of his/her level of dementia. We must consider attempts to provide the core psychological needs (love, comfort, attachment, inclusion, occupation, identity).
3. Promote positive health
4. All action is meaningful
5. Our work must contain elements of positive person work

How this applies to the care I give:

From: “*Dementia Reconsidered*”, Tom Kitwood, Buckingham, University Press 1998

Core Needs

Core psychological needs of a person with dementia and/or disability must be met to provide quality care. Use the “Implementation” column to note how you can meet each need.

Need	Description	Implementation
Love	“Unconditional acceptance” --- People with dementia often show an undisguised and almost childlike yearning for love. When we use the word “love,” we mean a generous, forgiving, and unconditional acceptance, and whole-hearted emotional giving without any expectation of direct reward.	
Inclusion	Total acceptance of the person and your efforts to make them feel included and connected to other members of the group will actually make care easier. As social beings, if this need remains unmet in persons with dementia, we see so-called attention seeking behaviors, tendencies to cling or hover, or disruptions.	
Attachment	Kitwood suggests, “Without the reassurance that attachments provide, it is difficult for any person, of whatever age, to function well. There is every reason to suppose that the need for attachment remains when a person has dementia; indeed, it may be as strong as in early childhood.”	

Need	Description	Implementation
Identity	As humans, our identity is conferred by others with the messages given through body language, tone of voice, words chosen and the level of respect given. It is, therefore, of paramount importance in partnering in the care of persons with dementia that we know in some detail each individual's life history. In this way, even if the person cannot hold on to his or her own identity due to loss of memory, we can hold it and help them retain it by telling the pieces of their story they are losing. Empathy in responding to the person also conveys and retains the other person's identity.	
Occupation	This is a term we do not often use except when we have a paid position. In the context of person centered care, it means for the person with dementia to be involved in a significant way in the process of life using their remaining abilities. If a person is deprived of meaningful, rewarding "work", their abilities atrophy and their self-esteem becomes damaged.	
Comfort	Folks with dementia have a special need for our warmth and compassion to soothe their anxieties and sorrows.	

Resident Rights

Residents have the right ...

- To be treated as individuals with dignity and respect
- To be free from mental, emotional, social, and physical abuse
- To be fully informed of the setting's approach and capacity to serve cognitive impairments
- To be assured choice and opportunity for decision making
- To be assured privacy
- To be given the opportunity to take risks in order to maximize independence
- To have immediate access to records and to be assured that records are confidential
- To be assured that no chemical or physical restraints will be used except in extreme cases in efforts to provide safety to those around the resident and to themselves and only on a short term basis
- To be able to choose services and be involved in decisions that are made
- To be fully informed of all rights and rules when applicable



F-Tags

f240:
quality of life

f241:
dignity

f242:
self-determination and participation

f319:
mental and psychosocial adjustments

f223:
abuse

f246:
accommodation of needs

f309:
quality of care

f157:
notification of changes

f163:
be fully informed

Alzheimer's Disease Bill of Rights

From: Bell and Troxel, The Best Friend's Approach.

“i heard a story about a gentleman who walked around yelling, “horse! horse!” the staff labeled him as agitated and usually avoided him because his yelling was so annoying. they eventually decided to talk to the family about this “behavior.” the family replied that when he was in his twenties he took care of horses. with this understanding, they brought in a saddle, reins, appropriate cleaning supplies, and pictures of horses and filled his room with items familiar to him. his yelling diminished, and he would clean the saddle and reins for long periods of time.”

—from “creating moments of joy for the person with alzheimer’s or dementia”, by jolene brackey

Residents have a right ...

- To be informed of one’s diagnosis
- To have appropriate ongoing medical care
- To be productive in work and play as long as possible
- To be treated like an adult, not a child
- To have expressed feelings taken seriously
- To be free of psychotropic medications if at all possible
- To life in a safe, structured and predictable environment
- To enjoy meaningful activities to fill each day

Ways to Implement Person Centered Care

Determine specific ways that you can contribute to person centered care practices. In the “Specific Example” column, write in an example of how you can implement each interaction,

From: *Positive Person Work: Defining the types of interactions that maintain personhood.* (both for the caregiver and the person who receives care.) Taken from the *Journal of Clinical Ethics*, Volume 9, Number 1, pp. 23-34. Written by Dr. Tom Kitwood.

Interaction	Description	Specific Examples
Recognition	<p>Both the care-receiver and care giver are acknowledged as separate persons affirmed in their uniqueness.</p> <p>Recognize the person for who he or she is and who he or she has been. Greetings and introductions are a routine part of the day. Everyone needs to hear their name spoken, preferably hourly.</p>	
Negotiation	<p>Both persons are consulted about their preferences, desires and needs. Much negotiation takes place over simple everyday issues, (wake-up times, meal times, etc.). Each person (care receiver and caregiver) needs to feel some degree of control over the care given and received.</p> <p>Personal preferences honored. Alternative activity choices are routinely provided. Some choice provided on issues of food preference.</p>	
Collaboration	<p>The hallmark of care is NOT something “done to” a person who is cast into a passive role; it is a process in which his or her own initiative and abilities are involved. The care becomes a partnership agreement.</p> <p>Build on abilities. Not “doing to” but “with”. Collaborate on environment of care.</p>	

Interaction	Description	Specific Examples
Play	<p>Whereas work is directed toward a goal, play, in its purest form, has no external goal. It is simply an exercise in self-expression--an experience that has value in itself. Because of the sheer pressures of survival and the discipline of work, most adults have only poorly developed abilities in this area.</p> <p>Accepting spontaneity. Not childish but perhaps childlike. Adults may need permission to play.</p>	
Timalation	<p>A fancy word to describe appealing to your senses and meeting those primal needs without the intervention of intellectual understanding. For example, massage and aromatherapy.</p> <p>Aromatherapy, hand massage, pleasing & soothing sounds, props to provide tactile stimulation.</p>	
Celebration	<p>The ambience here is expansive and jolly. It is not simply a matter of special events, but any moment at which life is experienced as intrinsically joyful. The experience can become almost spiritual.</p> <p>“Share” our celebrations rather than “create” celebrations.</p>	
Relaxation	<p>Of all forms of interaction, this has the lowest level of intensity and often the slowest pace.</p> <p>Respecting individuality and offering a variety of relaxation avenues, i.e., TV, relaxation tapes, guided imagery, storytelling, quiet/alone time.</p>	

Interaction	Description	Specific Examples
Validation	<p>Validate the life experiences of each other. Know the life story and what the essence of this person may be. The heart of the matter is acknowledging the reality of a person's emotions and feelings and giving a response on a feeling level.</p> <p>Know the person's story; what is and has been the essence of that person? Validate their life experience. Caregivers must be emotionally available to care receivers.</p>	
Holding	<p>To "hold" in a psychological sense, means to provide a safe psychological space where hidden traumas, conflicts, and fears can be explored without fear. Psychological holding in any context may involve physical holding, too.</p> <p>Demonstrating consistent behavior acceptance. Give individual recognition (hugs, thank-you's). Get rid of terms like "bibs", "diapers" as they reduce dignity for adults.</p>	
Facilitation	<p>At its simplest, this means enabling a person to do what otherwise he or she would not be able to do, by providing those parts of the actions – and only those – that are missing.</p> <p>Creating a "prosthetic" environment. Giving positive direction instead of constantly having to say "No, you can't do that," "No, you can't go there."</p>	

95 percent of what we know about alzheimer's disease we have learned in the past 15 years. scientists are making great strides toward better treatments, preventions and a cure.

Examples of Person Centered Care

- Understand what reality is for them
- See past their disability and find their strengths
- Relate to them as one human being to another
- Help them to hold on to and express their individual identities
- Help them to make the most of their strengths and abilities
- Help them to be as independent as possible while depending on us for any assistance they need
- Enable them to make choices and take reasonable risks
- Help to compensate for the effects of their dementing illness
- Help them to feel included and stay part of the social world
- Help them to feel respected, valued and wanted
- Help them to feel safe and secure
- Support them while they express their feelings
- Make an effort to understand their communication and help them to understand us
- Treat them as we would wish to be treated ourselves

Building Relationships with Co-Workers

Building relationships with co-workers is vital to having a community of support. By having others you can depend on, you can reduce your stress level, leading to better care for your residents.

Answer the following questions.

Make a list of words you would use to describe your closest relationship, such as with a spouse, sibling, parent, child, or friend.

Make a list of words you would currently use to describe your relationship with co-workers.

Look for similarities and differences. What can you do to make your relationship stronger with co-workers?



F-Tags

f223:

abuse

f224:

staff treatment of residents

f225:

potential employees

f240:

quality of life

f241:

dignity

f497:

regular in-service education

Ways to Help You!

- Staff input
 - Care plans are a work in progress, look for ways to incorporate what's working now into them.

- Visualize
 - You can be successful! Sometimes it helps to visualize success.
 - Use visualization to find a peaceful place.

- Compliment others and be willing to accept compliments
 - We're often quick to "blow off" compliments. We should receive them and acknowledge what we've done well.
 - Others need compliments, too!

- Use of the 'buddy' system
 - Find a buddy that can relieve you when you truly need a break.
 - Be willing to do the same in return.
 - Don't take advantage—if you abuse the privilege, your buddy won't be there for you for very long.

- Banish gossip!

- Have fun!

- Don't be afraid to ask for help. It is a sign of strength, not weakness.

Stress!

Stress, in itself, is not bad. Some stress is necessary just to live. Stress becomes harmful when it gets out of hand. When this happens, stress becomes distress. **Distress** affects dementia care because when professional caregivers are stressed out:

- The quality of care is reduced
- The caregiver's quality of life is reduced
- The caregiver will eventually experience burnout
- Distress and strong feelings have a physical impact

What are your signs of stress?

signs of stress include:

- too little or too much sleep
- nightmares
- fatigue
- headaches
- diarrhea
- constipation
- backaches
- pain in joints
- pain in muscles

Coping is key to your health and to providing quality care. Prevention of stress is key. Learn about dementia so that you can understand the residents' behaviors and needs.

- Have realistic expectations of what residents can and can't do
- Accept your mistakes and be gentle with yourself
- Accept and enjoy your success

cope effectively when you do become distressed. become aware that you are distressed. look for physical signs such as unsettled stomach and headaches. feelings that you attempt to push down such as guilt, grief, and anger may also be a sign.

How do you know when you are in *distress*?

Coping Strategies

Find **support** among friends

- Allow for expression of feelings.
- Share similar experiences.
- Praise and offer encouragement.
- Take time out.
- Got to a quiet place, even if just for a moment.
- Take breaks when they are scheduled—think and talk about happy things.
- Change the pace of your work periodically.

Away from work

- On your way home, focus on one good thing that happened, not just on problems
- Talk about feelings with a family member or friend who will listen and not judge
- Participate in activities that are completely different than caregiving
- Exercise!
- Relax
- Don't be afraid to ask for help

How do you cope?

notes

Tab



Communication Strategies

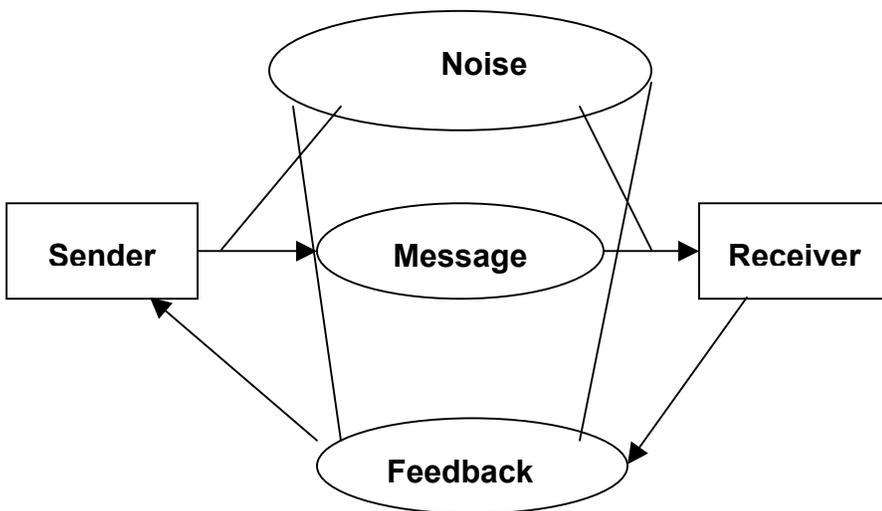
Objectives:

- Discuss the impact of verbal and non-verbal communication
- Examine and demonstrate techniques for promoting meaningful communication with persons with dementia
- Understand the correct use of validation and reality orientation

Communication Strategies

Communication is the exchange of information, ideas, and emotions. It involves sending and receiving of messages. It is how we related to one another. Communication is an important part of our personal relationships. Through communication, we convey our thoughts, wishes, and feelings. It helps us express who we are. Communication is more than talking and listening. It involves **attitude**, tone of voice, and body language.

The Communication Model



The **Sender** is the person who sends a message first, either verbally or non-verbally.

The **Message** is the information being sent, such as an attitude conveyed by a look or a verbal command.

The **Receiver** is the person who accepts the message. There may be multiple receivers.

Feedback is the response to the message, verbal or non-verbal.

i have often regretted my
speech, never my silence.
--anonymous

effective communication is
20% what you know and
80% how you feel about
what you know.
--jim rohn

Noise is what disrupts a message from being sent in its entirety. Examples of noise are a television, public address system, or other people talking. It could also be an object blocking the receiver from SEEING the sender. Noise can be internal, such as thinking about something else when someone is attempting to send you a message or impairments affecting thought processes, such as Alzheimer's disease.

When has noise affected your ability to communicate?

At home?

At work?

Out with friends?

How do you filter out noise?

Changes in Communication

A person with Alzheimer's disease often experiences changes in the way he expresses himself and the way he understands others. A philosophy of kindness, patience and respect goes a long way toward improving communication when a patient or loved one has Alzheimer's disease or dementia.

The way in which Alzheimer's disease affects communication will vary with each person. The person with dementia may find it increasingly difficult to express himself in words, and have trouble understanding what has been said. Those who interact with the person may recognize some of the following changes:

- Difficulty finding the right words
- Using familiar words repeatedly
- Inventing new words to describe familiar objects
- Easily losing train of thought
- Difficulty organizing words logically
- Reverting to speaking in a native language
- Using curse words
- Speaking less often
- Relying on nonverbal gestures more often



F-Tags

**f223:
abuse**

verbal abuse is defined as the use of oral, written, or gestured language that willfully includes disparaging or derogatory terms to residents or their families, or within their hearing distance, regardless of their age, ability to comprehend, or disability.

examples of verbal abuse include, but are not limited to, threats of harm; saying things to frighten a resident; such as telling a resident that he/she will never be able to see his/her family again.

**we have two ears and
one mouth so that we
can listen twice as much
as we speak.**

--epictetus

Listening Matters

Communicating with a person affected by Alzheimer's disease requires patience and understanding. First and foremost, you must be a good listener. When helping the person communication:

- **Be patient and supportive**—Let him or her know you're listening and trying to understand what he or she is saying.
- **Show your interest**—Maintain eye contact.
- **Offer comfort and reassurance**—If the person is having difficulty expressing himself, let him or her know it's alright and provide encouragement.
- **Give him or her time**—Let him or her think about and describe what he or she wants. Be sure not to interrupt.
- **Avoid criticizing or correcting**—Listen, and try to find meaning in what is being said.
- **Don't argue**—Arguing only makes things worse.
- **Offer a guess**—Try to help him or her out, but be careful not to cause frustration.
- **Focus on feelings, not facts**—Sometimes what's being expressed is more important than what's being said.
- **Limit your distractions**—Find a place that is quiet, so that you won't be interrupted.
- **Encourage him or her to communicate nonverbally**—Ask him or her to point or gesture.

Responding

Experts suggest the following strategies for responding:

- Remember that communication is more than the use of language. Nonverbal communication should reinforce the words. When helping someone with dementia to undress for a bath, for example, use non-controlling actions.
- During everyday activities, take the opportunity to convey warmth through touch and language. One Alzheimer's patient in a nursing home once told an aide that she felt like she was in a car wash when she was given her bath.
- People with dementia process verbal information more slowly. Don't give rapid instructions. Simplify, clarify and reassure.
- Ask questions requiring only yes or no answers. This decreases anxiety and frustration, allowing for simple communication.
- Speak gently and slowly in clear distinct tones on an adult level. High pitches and loud voices can frighten an AD individual, put the patient on the defensive and/or illicit a fight or flight response.
- In later stages of Alzheimer's disease, try to communicate in the person's original language.
- Approach the AD individual from the front. This compensates for decreased peripheral vision, decreases anxiety and avoids a startling response.

he knew
if you think we don't appreciate
or maybe didn't see
how kind and gentle you all
were, how thoughtful you could
be:
in all our days of being there we
never saw or heard
an unkind touch or gesture, an
impatient deed or word.
instead, through all your busy
days and nights of quiet care,
whenever he-or we-looked up,
we saw you standing there,
to take away the growing pain,
bring bedding fresh and clean.
your tender words-we know he
heard. your smiles were not
unseen.
a birthday cake to celebrate his
gentle, loving life;
a song to lift the spirits of his
children and his wife.
a better man there never was,
nor ever will there be,
so loved by us in life, and now
for all eternity.
in years to come, please think of
us and that short time we
shared,
and know deep in your hearts,
he knew...how very much you
cared.

*– by donna j. warlick, for wilburn
m. warlick*

**i think it would be interesting if old people got anti-alzheimer's disease where they slowly began to recover other people's lost memories.
--george carlin**

- “Cue” the AD individual by stimulating several senses. If the individual may need to use the bathroom, take him/her there and show him/her the toilet, and ask, “Do you have to use the toilet?”
- Use systematic trial and error to develop a “dictionary” to identify what the AD individual needs. When you think you understand what the individual is trying to communicate, help finish the sentence or complete the task rather than letting the person continue to struggle.
- Keep tasks simple and manageable; give brief, one-step directions and break down tasks in as few words as possible. This decreases confusion and compensates for lost memory and impaired ability to sequence. Breaking tasks into small parts offers potential for success and relies on more intact residual memory.
- Praise successes and emphasize the positive. Too much focus on loss is defeating.
- Avoid rushing the AD individual. Allow sufficient time for a response. If there is none, repeat the question or statement exactly as it was phrased the first time. If there is still no response, reword and simplify further.
- Stay flexible. Don’t arbitrarily select a particular routine, and then insist on maintaining control. If the person resists taking a bath in the morning, try later.

Verbal and Nonverbal Communication

Verbal communication is the words we use and how we use them, including:

- Tone
- Pitch
- Rate
- Pause

Nonverbal communication is the actions that communication, such as:

- Gestures
- Facial Expressions
- Postures

The importance of nonverbal communication is high. Communication is **10%** verbal. How we say something is more important than what we say. The ability to understand verbal communication becomes more difficult with Alzheimer's disease. People with Alzheimer's disease understand nonverbal communication long after the ability to understand spoken word has been forgotten.

Non-verbal strategies for effective communication

- Remember that your mood will be mirrored
- Approach the person from the front so that you don't startle
- Establish eye contact
- Speak at eye level whenever possible
- Use gentle touch to calm or reassure a person
- Point or demonstrate where you want the person to go or what you want them to do

electric communication will never be a substitute for the face of someone who with their soul encourages another person to be brave and true.

--charles dickens

don't talk louder unless a person has a hearing impairment.

Verbal strategies for effective communication

- Use a calm, gentle voice
- Call the person by name
- Identify yourself
- Use short, simple sentences
- Speak slowly
- Eliminate distracting noises
- Use familiar words
- Give simple choices
- Give one instruction at a time
- Allow enough time for a person to respond
- Remember that you are speaking to an adult, even when using simplified language
- Answer a frequently asked question a few times, in a calm voice, reassuring the person asking

Common pitfalls to avoid

- Don't talk louder unless a person has a hearing impairment
- Avoid commands or a demanding tone of voice
- Don't ask questions that rely on memory
- Don't argue

Validation vs. Reality Orientation

Validation (The Feil Method) is acknowledging another person's feelings. Think of a time in your life when you told someone how you felt, and the response from the person was that you didn't feel that way. How do you feel about that type of response? Wonder how would they know how you felt? Did you ask why you couldn't feel that way?

Describe when this has happened to you and how you felt about it.

Remember, that behaviors are an attempt to communicate. There is a reason behind all behaviors, even in the most confused person. Ignoring emotions that produce behaviors won't modify the behavior. In fact, often it makes it worse.

Ways to Validate

- **Become part of the person's reality**—regardless of when or where that might be
- **Acceptance**—to accept someone's reality doesn't mean that we have to lie or agree with something that isn't true
- **Feelings into words**—Naming the feeling behind the words isn't the same as agreeing
- **Acknowledgement**—Acknowledging feelings will help the caregiver react sensitively and gently to the needs of the resident

naomi feil, m.s., a.c.s.w., is the developer of validation.

she was born in munich in 1932, and grew up in the montefiore home for the aged in cleveland, ohio, where her father was the administrator and her mother, the head of the social service department. after graduating with a masters degree in social work from columbia university in new york, she began working with the elderly. between 1963 and 1980, feil developed validation as a response to her dissatisfaction with traditional methods of working with the severely disoriented older people who were her clients.

feil is the executive director of the validation training institute. her books have been translated into french, dutch, german, italian, finnish, danish, and swedish.



F-Tags

f154:

right to be fully informed

Reality Orientation

Reality orientation is the process of attempting to orient a person to the current day, time, and place. In the early stages, a person might prefer to be oriented to reality, but short explanations should be used. When it becomes stressful to a person with Alzheimer's disease to hear this type of information, reality orientation should no longer be used. As the disease progresses, the ability to understand new information decreases and becomes frustrating. Reality becomes based on past memories because that is the area of the brain that is still functioning. Unwanted effects of reality orientation:

- **Hostility**—reminding a person of what they can no longer do can lead to anger and aggression
- **Loss of trust**—Questioning someone's reasoning may sound like questioning someone's credibility or accusing them of lying
- **Unnecessary grief**—How many times would you want to hear that your loved one is dead?

Therapeutic Fibbing

Therapeutic fibbing is the use of telling fibs or lies in an effort to provide comfort or to calm. Therapeutic fibbing or lying may be used in some circumstances, but only with caution. We are never sure how much information a person may be able to process or remember. Sometimes, it is used thinking that it will be helpful or kind to someone with dementia. However, it should only be used when absolutely necessary, look for other ways to calm and support the resident, such as redirection.

notes

Tab

Understanding Behaviors

Objectives:

- Understand how and why behaviors become challenging
- Name ways to prevent behaviors
- Demonstrate techniques for responding to challenging behaviors
- List emotions a person with dementia is likely to experience and how to respond to them

Understanding Behaviors

From the New York Consortium for Alzheimer's Research and Education

Behavioral problems in people with Alzheimer's disease are common and serious. They can occur at any stage of the disease. **90%** of people with dementia experience some form of behavioral disturbance during the course of their illness. In a recent survey of a nursing home, **100%** of the residents had experienced a behavioral disturbance within the past month. Behavioral symptoms are described by caregivers as highly stressful and are a common reason cited for institutionalization.

There are several terms for these behaviors: **non-cognitive symptoms, behavioral symptoms, and agitation**. Agitation is the most commonly used term and it encompasses a broad range of disruptive behaviors. In its mild forms the person can be snappy and short-tempered in ways that are out of character for him or her. The person may display restlessness such as pacing, packing and unpacking, aggression, and insomnia. More severe agitation includes physical and verbal aggression such as yelling, cursing, pushing, hitting and biting. Delusions and hallucinations are other behavioral symptoms that can be very distressing to both the person with AD and his or her family.

Delusions are false beliefs that the person with AD insists upon despite a lack of evidence or even evidence to the contrary. Dr. Alzheimer's first patient, Augusta D., had prominent behavioral symptoms including hallucinations of a child crying and delusions that her husband and Dr. Alzheimer were conspiring against her. The most common symptom of this sort seen in people with Alzheimer's disease is suspiciousness or paranoia; usually that someone is stealing their property. The person not being able to find his or her things, because he or she has forgotten where they were put, often prompts these suspicions.

he thinks that every time i go down to the basement that i am meeting with a lover! he can't stand to have me walk out of the room...he follows me everywhere.

--from understanding behaviors

she is fine until we try to get her to the shower. then all hell breaks loose...swearing like a sailor, kicking, biting, punching. i've have never seen anything like it!

--from understanding behaviors



F-Tags

f221/222:
resident behavior and facility practices

f223:
abuse

f224:
staff treatment of residents

delusions are false beliefs that the person with ad insists upon despite a lack of evidence or even evidence to the contrary

hallucinations are sometimes misperceptions of normal events (for example a patient interpreting a shadow as an intruder in the apartment) or they can be brain “tricks” that create vivid images or sounds that do not conform to actuality.

The delusions can be short-lived, that is, often the person can be distracted from them or simply forgets the concern [“two minutes later, he’s as gentle as a lamb, as if nothing had happened.”] At times however, the person can become angry or aggressive in the context of a delusional belief.

Hallucinations can occur in any of the senses. People with dementia might see or hear people that are not there. Less often, they might smell strong odors such as burning rubber that are not detectable to anyone else. These hallucinations are sometimes misperceptions of normal events (for example a patient interpreting a shadow as an intruder in the apartment) or they can be brain “tricks” that create vivid images or sounds that do not conform to actuality.

What causes these behaviors and symptoms? The behaviors can sometimes be understood as reactions to circumstances that the person can no longer manage: the person with AD may be resorting to yelling or throwing things when he or she cannot find the words to express needs. The person with AD is less able to fend for him- or herself, more dependent upon others, and sometimes frightened of being left alone. This can explain why some people with dementia cling to their spouses and follow them around. Other aspects of these behaviors derive more directly from the brain disease: the loss of brain tissue and brain chemicals that causes memory deficits can also impact on the person’s ability to control emotions and behavior.

Management of these behaviors must take into account what the person’s needs are and to what extent he or she can express his or her needs. The person might be in need of company, might be bored, or have more basic needs that cannot be expressed directly – e.g., pain related to an undetected medical condition. So the first step in management is to look for patterns to the behavior. Does it occur only when the person is to be bathed? Has the person developed a fear of the shower that precipitates the agitation and can

it be controlled by a common sense measure like the use of a sponge bath? The next step is to provide social support, engaging activities, exercise and relief from discomfort. Structured activities such as attending a day program or daily walks can provide both social support and mental engagement. These common sense efforts to enhance the daily quality of life can diminish the frequency of agitated behaviors.

Management of agitation often requires consultation with a dementia specialist. Medications, most commonly antipsychotics, play a significant role as their use can diminish irritability and agitation. In the past there was a justified reluctance to use medications for this purpose as the older medications frequently produced side effects. The advent of the newer “atypical” antipsychotics has brought safer and more easily tolerated medications to use. However, there are not as yet, any medications that are FDA approved specifically for treatment of agitation, delusions or hallucinations in Alzheimer’s disease.

This will likely change over the next five years. The National Institutes of Health (NIH) and National Institutes of Mental Health (NIMH) are currently sponsoring the Clinical Antipsychotic Trials of Intervention Effectiveness in Alzheimer’s Disease (CATIE-AD), a large-scale evaluation of the role of these newer medications for the treatment of the behavioral symptoms discussed here. This study involves more than two dozen centers across the country and will enroll over 500 participants. The questions asked by this study are vital: Which of the treatments in current use are effective? What are the safety risks? For whom will these treatments work? The answers to these questions will influence how we will manage these disabling behaviors and will bring caregivers more effective means of relieving these symptoms.

**the significant problems
we face cannot be solved
at the same level of
thinking we were at
when we created them.
--albert einstein**

my mother enjoyed rearranging her jewelry and would spend a great deal of time at it. just make sure that anything of value is removed.

—milford/northbridge support group

Human Emotions

It is a basic human need to express emotions.

There are four basic human emotions:

- Joy (pleasure, love, happiness, sexuality)
- Anger (rage, hate, displeasure)
- Fear (guilt, shame, anxiety)
- Sadness (misery, grief)

Which emotions do you see most often in your residents?

Which emotions would you prefer to see in your residents?

People with Alzheimer's disease often experience all of these, but feelings of fear, anger, loneliness, embarrassment, worthlessness, and isolation are most common. Many people believe that people retain their emotional link to the world regardless of how close to the end of life a person is.

Responding to Feelings

Responding to the feelings *behind* behaviors is key to understanding what the behavior may be trying to communicate.

How to respond to feelings

- Enter the other person's reality
- Look for the feelings behind the words or behaviors
- Empathize—walk in their shoes
- Be non-judgmental
- Respect their needs—treat the person as a valued human being
- Communicate comfort, warmth, and praise
- Your emotions will be mirrored—monitor yourself
- Smile!
- Put the person's feelings into words
- Allow for negative feelings—Provide comfort, and don't brush them off or disagree
- Reminisce—Allows for use of the memory that is still there
- Share feelings—It's okay to talk about how you feel

**no soul is desolate as long as
there is a human being for
whom it can trust and
revere.**

--george elliot

Problem Solving Behaviors

Related to:	Specific Issue	Problem Solving Steps
The Task	Too complicated	Breaking down tasks into small, concrete steps is an effective technique that enables a person with Alzheimer's disease to succeed
	Too many steps combined	Combining too many steps together may increase confusion, eventually leading to failure of the task
	Not modified for increasing impairment	As the person's functioning declines, more help is needed. Also, consider other impairment such as declining vision or hearing
	Unfamiliar	People with Alzheimer's disease gradually lose their ability to learn new things. Focus on activities that the person can still do
The Environment	Too Large	Too much space can be confusing. Try smaller rooms or section off part of a larger room. Also, encourage small groups
	Too much clutter	Sometimes there is too much in the environment for a person to absorb. Simplify the environment as much as possible
	Excessive stimulation	When there is too much going on, such as music or conversations, it may be distracting and result in anger, frustration, or withdraw
	No orientation information or clues	As the disease progresses people with Alzheimer's disease need more cues to negotiate the environment
	Poor sensory environment	As a person ages, their ability to sense changes. Usually, one or more of the sense is impaired with dementing illnesses
	Unstructured	People with Alzheimer's disease need a routine and daily structure to feel secure. This reduces stress, but be willing to be flexible

Related to:	Specific Issue	Problem Solving Steps
	Unfamiliar	New environments can be confusing, focus on activities the person is used to
Physical Health	Effects of medication	People with Alzheimer's disease are vulnerable to over-medication or to reactions from drug combinations.
	Impaired vision or hearing	Both of these can affect a person's ability to understand what's being said.
	Acute illness	Urinary tract infections, pneumonia, and fever may increase confusion.
	Chronic illness	Angina, congestive heart failure, or diabetes can affect a person's mood or level of functioning.
	Dehydration	Many people with dementia do not get enough fluids because they no longer recognize the sensation of thirst or they forget to drink.
	Constipation	This can be very uncomfortable and lead to bowel impaction.
	Depression	Many symptoms of depression resemble those of dementia. In addition, it is common for people with dementia to have depression.
	Fatigue	Disrupted sleep patterns can cause angry or agitated behaviors.
	Physical discomfort	If immediate needs are not being met, then the person experiences discomfort.
Miscommunication		Communication between the caregiver and the person with Alzheimer's disease or dementia is extremely important—and often the most difficult—part of the caregiving process. People with dementia may become angry or agitated because they do not understand what is expected of them. Or, they may be frustrated with their inability to make themselves understood.

The 11 W's

The 11 W's offer an easy way to assess behaviors. The following chart shows what each "W" is and gives you space to take notes. The final column is for an activity at the end of this module.

"W"	Notes	Activity
Who actually has the challenging behavior—the person or the caregiver?		
What is the specific problem or behavior?		
Why does it need to be addressed? Who is it hurting/bothering?		
What happens just before the behavior (triggers)?		
Where does the behavior occur (environment)?		
What does the behavior mean?		
When does the behavior occur (time, task)?		
What is the time, frequency, and pattern of the behavior?		
Who is around when the behavior occurs?		
What is the outcome of the behavior?		
What is the DESIRED change or outcome of the behavior?		

Preventing Behaviors

Not all behaviors are problems. If behaviors cause difficulties for the person, caregiver or others, the best strategy may be to do nothing. If a particular behavior is a challenge, try to understand it first.

Techniques for prevention:

- **Diversion or distraction**—moving or shifting the person's attention from one stimulus to another
- **Removal**—separating the person from the situation or stimulus
- **Redirection**—moving or shifting energy from one activity to another
- **Task breakdown**—separating an activity into smaller and simpler steps
- **Stimulus control**—provide limited choices
- **Environmental manipulation**—control noise level, lighting, and temperature
- **Reassurance**—provide a sense of safety and security
- **Setting limits**—take control of the situation and not allow certain actions or activities to happen

**it is important to know
what *person* the disease
has, not what disease the
person has.**

--sir william osler

**what i perceive the
behavior to be...is just
another expression of
need.
--unknown**

Responding to Behaviors

Here are some common behaviors and the typical meanings.

Anxiety/agitation

- General unrest, uneasiness, or apprehension. These may include hostile actions, such as shouting, screaming, and object throwing
- Response to misinterpretation of environmental factors including other people

Problematic wandering

- Leaving an area that creates discomfort, expending excess energy, discomfort, exhibiting lifelong patterns of work or time schedule
- This can be a minor irritation to a safety concern. Sometimes wandering can be caused by a delusion, such as the person searching for a loved one. Whatever the cause, wandering often requires careful and creative management to prevent injury

Aggressive reactions

- Usually directed at the caregiver or another individual. Hitting, pushing, or threats are most common and occur when a caregiver attempts to help an individual. Can cause injury to themselves or another person.

Rummaging

- Looking for something meaningful or comforting

Repetitive Crying Out

- Unresolved pain or discomfort

notes

Tab

Activities of Daily Living

Objectives:

- Identify causes for resistance to ADL's
- Describe strategies that promote participation in personal care
- Identify and demonstrate possible techniques for managing ADL's
- Identify signs of abuse and neglect

My Own ADL's

What did you do to get ready this morning?



F-Tags

f164:
privacy and confidentiality

f240:
quality of life

f241:
dignity

f242:
self-determination and participation

f223:
abuse

f224:
staff treatment of residents

f246:
accommodation of needs

f310:
activities of daily living

f323-324:
accidents

Activities of Daily Living

Personal care is the most private, intimate activity that we do for ourselves. Many people who have had caregivers assist them with personal care remark on how difficult it is to give up taking care of themselves.

Thinking on the previous activity, what emotions and thoughts did you have once you were told that someone else would be taking care of you now?

Providing personal care requires great sensitivity. It can seem invasive, and bring up reminders of abuse, neglect, or other memories that have been suppressed. Alzheimer's effects the brain in several ways that relate to personal care.

Affects of Alzheimer's disease on the brain

- Memory loss
 - Forgets to complete an ADL
 - Forgets that an ADL has been completed
 - Decreased attention span
 - Loss of interest due to distraction during ADL
 - Inability to place tasks in a logical order
 - Unable to remain still
- Impaired judgment
 - Lack of regard to safety
 - Privacy may or may not be an issue

- Disorientation:
 - Forgetting people, time, and place
 - Inability to understand relationship with caregiver
 - Emotional upset
 - Frustration
- Loss of ability to communicate
 - Inability to reason or rationalize
 - Unable to ask questions or understand answers
- Difficulty with motor skills
 - Unsteady gait
 - Increased falls
 - Inability to coordinate movements

remember me

**when you look into my eyes
and you see the loss and the fear
don't be afraid for me or cry for me
remember me!**

**when you see me wander off or
take
a wrong turn
don't fear for my safety
take my hand and remember me!
when i say something backwards
or jumble my words
just be patient and remember me!**

**when i make faces or say silly
things
laugh with me and remember me!
when i rub my head or look away
i feel the sense of loss and fear i'm
searching for the right turn
i'm searching for the right words
i'm trying to remember me!**

**— by tracy mogley, diagnosed
with early on-set alzheimer's**

he can't resist if you don't insist

remember the principles of person centered care when assisting with personal care

Strategies for Participation

It is your responsibility to anticipate problems or events. If you can anticipate, you can successfully prevent problems. If you cannot anticipate the problems, you should have an established method for correcting problems or events as they occur. Provide a routine, but remain flexible--consistency leads to success.

General steps

- Establish rapport with the person before attempting the ADL
- Always talk in a calm voice, no matter what the situation
- Do not attempt to use reason or logic
- Do not rush—allow enough time for the person to complete all or parts of it
- Avoid arguing
- Focus on abilities and encourage independence.

Approach

- Knock before entering and announce yourself
- Close the door while assisting with personal care
- Keep other residents and staff members from entering while assisting
- Allow the person to feel in control by offering simple choices
- Encourage the person to do as much for himself or herself as possible
 - Give help before the person becomes frustrated.

- Praise for small success
 - Give compliments as soon as they are earned, do not wait to reward positive behavior
 - Give encouragement freely and frequently
- Provide for privacy
 - Respect the person's level of modesty
 - Remember that their generational needs may be different than yours
- Do not keep an individual waiting
 - Have all items ready in advance
 - Leaving the room creates a distraction and leads to inability to comply
- Demonstrate what you want done
 - Help the person start the task
 - Break the task into small steps
 - Sequence the steps to help simplify the task
- Stop when frustration occurs
 - Do not continue once frustration is apparent
 - Stop and try again later
 - Have someone else try
- Make sure the environment is appropriate for personal care
 - Well lit
 - Clean
 - Free of clutter
 - Warm
 - Soothing music that the resident would enjoy
- Find out preferences from person's family

never take over an activity because the person is slow, this takes away from remaining abilities and independence

i don't see how an article of clothing can be indecent. a person, yes.

--robert a. heinlein

there must be quite a few things that a hot bath won't cure, but i don't know many of them.

--sylvia plath

ADL Tips

Dressing

- In the early stages, use gentle reminders when clothing needs to be changed, this can be embarrassing
- Layout clothes for a person who can dress independently
- Limit choices on clothing options
- Encourage the joy of 'dressing up.' Offer jewelry, hair ribbons, etc
- In the late stages, you may want to give the person something to stroke or manipulate while you do thing, they are no longer able to do.

Bathing

- Keep the routine consistent
- Ensure as much privacy as possible
- Ensure adequate lighting

In the middle stages:

- Have bath water and supplies ready
- Separate bathing from hair washing
- Remember that a daily bath may not be necessary
- Keep the bathroom as warm and as homelike as possible
- Keep distractions to a minimum

In the late stages:

- Gently coach the person during each step
- Using cupping—put the person's hand over yours

Toileting

People can suffer from incontinence for a variety of reasons

- Medical conditions like urinary tract infections
- Stress can cause leakage
- Bladder irritants like coffee and citrus juice
- Inadequate hydration—lack of fluid will make the urine more concentrated causing irritation to the bladder that can lead to incontinence

Evaluate incontinence

When do accidents occur?

- If only wetting at night, decide if waking him or her up in the night is appropriate
- Establish the person's typical toileting pattern and try to stick to it
- Did the incontinence begin suddenly?
- A physical illness or side effects from medications should be considered
- Look for increased confusion, as it may be a sign of an acute illness or stroke
- Where is the person voiding?
- If the person is on the way to the restroom when the accident occurs, this suggests stress incontinence
- If the person is voiding in places like wastebaskets and closets, make sure the restroom is clearly marked and unobstructed.

Take action

- Have a medical evaluation to rule out physical illness or medication side effects
- Check the environment to make sure that toilets are clearly marked with words or pictures



F-Tags

f316:

incontinence

**i don't like the way you
are feeding my best
friend.
-one staff member to
another, serenity nursing
home, south africa**

- Make sure the toilet is visible—keep the door open, lights on, and lid up
- Encourage independence by simplifying clothing, not rushing the person, and allowing them to do as much as they can
- Look for nonverbal cues such as picking at a zipper and know the person's words for signaling their need
- If accidents occur, reassure the person, don't scold, and be discreet
- Adequate hydration is essential, don't restrict fluids in order to reduce accidents

Eating and swallowing

Three goals of nutritional care:

- Ensure adequate nutrition and fluid intake-- A weight loss of 10 pounds a month is enough to cause malnutrition. Malnutrition can increase confusion
- Make eating a social activity as well as a pleasurable sensory experience
- Independence--It has been said that eating is the hardest activity to give up to another person.

Action steps:

- Ensure adequate fluid intake
- Offer liquids every two hours
- Look for creative ways to offer liquids, such as as a part of an activity or items such as Popsicles and ice cream
- Keep in mind that people with dementia may not recognize the signals for thirst or may forget that water is nearby. Be sure to remind your residents often.

- Respond to appetite changes, the person may have a loss of appetite or forget that they have eaten
- Reduce the effects of declining perceptual abilities. Use plates and placemats that are solid colors and contrast with each other
- Limit choices and allow for focus by offering one food at a time and one utensil
- Reassure the resident calmly when the person asks questions or are concerned
- Monitor agitation
- Constant pacing burns extra calories
- Make sure physical needs are taken care of
- Serve the agitated person first
- Decrease mealtime confusion
- Minimize distraction
- Limit number of people to three or four at a table
- Sit opposite of the person if you need to monitor swallowing or watch for pocketing of food
- Sit beside a person if you are guiding their hands for self feeding
- Join them!

**i'd rather one should walk
with me than tell me the
way.**

--edgar a. guest

signs of abuse
during adl's, look for:

- **bruises**
- **lack of eye contact**
- **unusual response to physical touch**

if you notice any of these during personal care, report them to the charge nurse immediately, as it may be a sign of abuse.

Sleeping

Sleeping becomes a problem because of:

- Age
- Internal clocks being disturb by the disease process
- Lack of exercise
- Pain, medication, and depression
- Sleep disturbances are part of the disease process

Action steps:

- Keep a log of sleep behaviors
- Look for side effects from medications
- Evaluate for depression
- Decrease caffeine consumption
- Increase physical activity
- Relieve pain at night
- Offer a bedtime snack
- Avoid upsetting activities in the evening
- Choose a sufficient lighting level

Even when all of these steps are taken, some individuals will still want to be up at night. Remember, 24 hour care is our obligation. Offer activities that are soothing at night.

When the resident gets up at night:

- Speak softly
- Gently reassure if there has been a nightmare
- Reassure him or her that he or she is safe and help them get back to bed

notes

Tab

Families

Objectives:

- **Empathize with feelings that persons with Alzheimer's disease and their families experience**
- **Identify and inform families of internal and external resources**
- **Identify strategies for building a positive relationship with the family**
- **Understand the unique opportunity to have a long term relationship with the family and resident.**

Family Feud!

Name emotions family members may have regarding their loved one.

Name emotions family members may have regarding putting their loved one in long term care.

Name ways that family members can help with the care process.

Name activities that families can do when they come to visit.

i cry

i cry. i cry.
 see me, know my name.
 please just one more time,
 remember who i am.
 i look in your eyes and see the
 mother who use to be.
 and i don't know how much
 longer we can endure.
 confused and afraid, nothing
 i can do.
 i cried today for what i've
 lost.
 i cried today for all the
 tomorrow's that well never
 be.
 i cry from loss, from not
 wanting to see another day of
 all this,
 but yet not wanting to ever
 let go.
 yes i cried today knowing it
 won't be long and she'll be
 gone.
 i cry because i can't do this,
 but must.
 i cry for my losses and the
 ones to come.
 i cry for me. i cry for her.
 i cry
 – by debbie estray

Helping Families Cope

Treating individuals with Alzheimer's disease necessarily involves **guiding and supporting** their caregivers as well. Stress and depression can take their toll on those who tend to the daily needs of Alzheimer patients. Unaddressed, these problems can affect the caregivers' performance and, in turn, the well-being of the people they care for.

It is common for caregivers to experience feelings of loss, especially if their lives and someone they love is changed by Alzheimer's disease. The natural phases of grieving usually involve denial, anger, guilt, physical symptoms, and eventually acceptance. However, it is important to know that everyone grieves differently.

Caregiver reactions

Caregivers may:

- Deny their loved one is ill
- Experience periods of helplessness, despair, and depression
- Experience changes in appetite or sleep patterns
- Get angry or frustrated with the person with Alzheimer's and caregiving tasks
- Withdraw from social activities and from friends, family and the person they care for

Guilt

Throughout the process of grieving and mourning, guilt is often the most prevalent feeling for caregivers. This guilt arises from:

- Thinking they could have done something differently
- Being able to enjoy life while their loved one may not
- Feelings that they have failed, especially if their loved has been placed in a nursing home
- Negative thoughts about the person with the disease — wishing her suffering would come to an end

- Conflicts with family members because they are uninvolved or critical of the care that's being provided

In many cases feelings of guilt are linked to unrealistic expectations. To help caregivers cope with the grieving process, suggest they:

- Confront their feelings
- Accept guilt as a normal part of loss and grief
- Find ways to forgive themselves
- Share their feelings with a friend, support group, therapist, or spiritual leader
- Learn to feel comfortable accepting and celebrating good things in their lives
- Coping with grief

There are ways that they can begin to cope with grief, including:

- Returning to some aspects of their daily routine
- Allowing time for physical exercise, play, and rest
- Trying to find humor — even in difficult situations
- Bringing balance to their lives by doing things they enjoy
- Preparing for what the future may entail

Denial

This helps keep our distance from horrible news, it protects us and helps us control how much information we let in and when.

Frustration

Families or caregivers may become angry when they don't understand what's going on, either the disease process or accessing resources. They may not know how to respond to their loved one who has trouble communicating, and they may not understand behaviors.

precious stone

my mother is like a stone

a beautifully polished
gemstone

sitting so peacefully alone

until the angels finally
claim her to be their jewel.

*— by lois weaver, for her
mother*

**when we find one of our
alzheimer's persons
crying, it usually helps to
take a few minutes to
talk with her about her
daughter and that she is
at work, and that her
daughter washes her
clothes, and comes for
breakfast. it only makes
her cry more to tell her
not to cry.**

--wilma mcdowell, cna

Isolation

As the disease progresses, family and friends may have begun to pull away from the primary caregiver, leading to feelings of being trapped and suffering from loss of close relationships.

Anger

Sometimes families think that their loved one is doing things on purpose, when it's really the disease process. They may be irritated by behaviors and attempt to control their loved ones by commanding and demanding.

Loss/grief

Many family members are grieving throughout the disease process, because their loved one looks the same, but in reality, has changed drastically. Familiar roles, money, friends, and other aspects of a normal life have been lost.

Letting go

Difficult emotions intensify when a loved one moves into a facility. A family member who has had the daily burden of care may no longer know what to do to fill the hours in a day. Sometimes this leads to feelings of relief, which can be almost difficult to cope with.

Conflict Resolution

Validating a family member's emotions can go a long way. Remember that all behaviors and actions are a form of communication, even in people who are not affected by Alzheimer's disease.

When helping families, be sure to speak in private. Only discuss matters that your facility wants you to. Know internal and external resources you can direct families to.

Overcoming denial

- Remember that denial can be healthy if it doesn't go on too long
- Educate in small doses, have brochures and written materials available
- Do not push too hard, give them time to adjust
- Encourage support group attendance
- Difficulty accepting change
 - Acknowledge their skepticism up front
 - Ask them to listen carefully to a suggestion
 - Ask them what they think might work
 - Ask another family member to be a mentor

Lack of understanding about Alzheimer's disease

- Direct them to an educational program
- Go through printed materials with them
- Use the internet and email appropriately



F-Tags

f226:

staff treatment of residents

f243-244:

participation in resident and family groups

f280:

care plans

**i believe more is caught
than taught.
--kay lloyd, director of staff
education, the
fountainview center for
alzheimer's disease,
atlanta, georgia**

Unrealistic expectations

- Invite them to care plan meetings
- Let them know the consequences of expecting too much from their loved one
- Describe staff goals and expectations

Critical-Angry-Never Happy

- Be sure you are listening to legitimate concerns
- Ask them to write out a list of what's wrong and what's working well
- Appoint one spokesperson from the staff or ask a third party to mediate
- Make sure your care philosophy and plan is clear to family members
- Give them feedback on how their criticism is received by staff

Internal Resources

Areas of Function

Dietary:

Housekeeping:

Medicine/Medical:

Billing:

Family Counsel:

Nursing:

Activities:

Social Services:

Other: _____

Other: _____

Other: _____

our vision is a world
without alzheimer's
disease

our mission is to
eliminate alzheimer's
disease through the
advancement of research
and to enhance the
quality of care and
support for individuals,
their families and
caregivers.

indianapolis office
9135 n. meridian street
suite b-4
indianapolis, in 46260
(317) 575-9620

fort wayne office
227 e. washington blvd.
suite 301
fort wayne, in 46802
(260) 420-5547

columbus office
1252 washington street
po box 547
columbus, in 47201
(812) 372-3755

Alzheimer's Association

Helpline (800) 272-3900

A telephone information & support service for families and professionals, available 24 hours a day, 7 days a week. Provides information about the disease, referrals to community resources, and support to those caring for someone with Alzheimer's. Please use the Helpline to access our other services.

The Companion

A free quarterly newsletter which includes information on the disease, caregiving issues, research, upcoming education programs, community resources and support groups.

Caregiver Support Groups

Support groups throughout Greater Indiana meet monthly to assist caregivers in decision-making, finding needed services and managing day-to-day activities. Meetings are listed in the newsletter and can be accessed through the Helpline.

Family Education Programs

Free programs for families are offered several times a month throughout the state. An overview program featuring a medical professional and a lawyer is frequently presented. In addition, specialized programs on topics such as nursing home expectations, communication strategies, and understanding behaviors.

Care Consultation

This program provides a licensed clinical social worker to help assist family caregivers in finding and coordinating services for persons with Alzheimer's disease.

Safe Return Identification Program

A national program designed to identify, locate, and return individuals with Alzheimer's who wander. There is a one-time registration fee of \$40; scholarships are available from the Alzheimer's Association.

External Resources

Adult Abuse Hotline	(800) 992-6978
AARP	(800) 441-2277
Alcoholics Anonymous	(317) 632-7864
Consumer Credit Counseling Service	(317) 266-1300
Community and Home Options to Institutionalize Care for the Elderly	(317) 254-3660
Dental Care Assistance	(317) 634-2610
Food Stamps	(317) 232-3608
Grocery Delivery Helpline	(317) 926-4357
Hearing Aids	(317) 259-8105
Home Repair	(317) 254-3660
Hoosier Rx	(866) 267-4679
IN Department of Mental Health	(317) 232-7094
Legal Aide--Senior Law Project	(800) 869-0212
Medicaid Intake Line (applications)	(317) 232-3608
Medical Equipment	(317) 283-1643
Medicare/Medicaid Questions	(800) 452-4800
Medicare/Social Security	(800) 772-1213
National Eye Care Project	(800) 222-EYES
Nursing Home Complaints	(800) 622-4484
Pets for Seniors	(317) 872-5650
Tax Preparation Assistance	(800) 829-1040
Veteran's Administration	(888) 878-6889
Utility Assistance	(317) 327-7700

Dementia specific resource guides are available by calling the Alzheimer's Association Helpline, (800) 272-3900.

**the human face is a picture
show of expressions. we
can often communicate
more with our eyes than
with words.**

--anonymous

Successful Family Visits

101 THINGS TO DO WITH A LOVED ONE WITH ALZHEIMER'S DISEASE

- 1) Rake leaves, weed flowerbeds
- 2) Arrange fresh or silk flowers
- 3) Water house plants
- 4) Force bulbs for winter blooming
- 5) Plant a tree
- 6) Make and care for an indoor garden or terrarium together
- 7) Take care of the fish tank
- 8) Feed the ducks
- 9) String Cherrios to hang outside for birds
- 10) Build a bird feeder or house to hang outside your loved one's window
- 11) Bring a bird book and see how many types of birds visit
- 12) Look at family photos
- 13) Create a photo album, framed photo collection or family tree poster to hang up
- 14) Make a scrapbook celebrating your loved one's lifetime
- 15) Write or tape your loved one's biography and give copies to the family
- 16) Read letters, listen to tapes or watch video letters from family or friends
- 17) Help your loved one write or tape letters to send to family or friends
- 18) Find a pen pal and help your loved one correspond with this new friend
- 19) Bring vacation photos, souvenirs post cards, maps and tales of your travels
- 20) Share your own favorite stories and memories
- 21) Talk about what you have both been up to since your last visit
- 22) Say "tell me more" when your loved one starts sharing a memory
- 23) Reminisce about a favorite summer, the first day of school, or the first kiss

- 24) Cut out and dress paper dolls
- 25) Play easy card games or work a puzzle
- 26) Play "Name That Tune" with records, tapes or music on the radio
- 27) Play charades
- 28) Play word or trivia games to keep the mind alert
- 29) Play board games together and keep a running score in your own tournament
- 30) Toss a ball or play horseshoes
- 31) Blow bubbles outside
- 32) Dress in team colors on a sports game day
- 33) Finish nursery rhymes or famous sayings
- 34) Name presidents, states or capitols
- 35) Remember great inventions or famous people
- 36) Have a spelling bee
- 37) Wind yarn for a knitting project
- 38) Work on sewing cards or do the mending
- 39) Work on a craft project together such as drawing, painting or sculpture
- 40) Make simple gifts for your loved one's grandchildren
- 41) Sand wood shapes
- 42) Make a collage from pictures cut out of a magazine
- 43) Make sock-puppets or paper-bag puppets and have a puppet show
- 44) Paint on a sheet and hang it on a wall
- 45) Color pictures or decorate paper placemats
- 46) Make paper butterflies for the room
- 47) Trace and cut out leaves
- 48) Cut up used paper for scratch paper
- 49) Mold with Play-Doh
- 50) Grow magic rocks
- 51) Sort objects such as poker chips or beads by shapes or colors
- 52) Organize a sewing or tool kit
- 53) Sort playing cards by suits or numbers
- 54) Make cream cheese mints, or other favorite candies
- 55) Bake cookies, homemade bread, or make a pie
- 56) Make a fresh fruit salad or homemade applesauce

my grandma

she was the first to change my bottom.

she was the one who spoiled me rotten.

we have grown so close in these 17 years.

now i can't help but burst in tears.

when she looks in the mirror and doesn't recognize her own face, i can't help but think how her brain is deteriorating at such a pace.

i know inside my soul is crying, and know i can even see grandpa's soul is dying.

deep down inside i know we'll be all right.

we're a strong family, we'll see the light.

i realize now the day will come and we'll be sad.

but we know it's in god's plan and things won't be so bad.

— by *janae cartmel*, written for *her grandma*

**a loving heart is the
beginning of all
knowledge.**

--thomas carlyle

- 57) Make homemade lemonade
- 58) Make homemade ice cream
- 59) Cook hotdogs outside
- 60) Make peanut butter and jelly sandwiches
- 61) Have an indoor picnic or afternoon tea party with your loved one's favorite foods
- 62) Enjoy a cup of a favorite beverage you've brought in your thermos
- 63) Bring a favorite recipe book to explore or to plan a meal together
- 64) Bring the musical instrument you play for a private concert
- 65) Teach your loved one to play an instrument
- 66) Listen to music, sing along with your loved one's favorites
- 67) Do wheel chair / walker dancing
- 68) Wash or polish silverware
- 69) Set or wipe off the dinner table
- 70) Sort laundry
- 71) Match socks
- 72) Straighten clothing drawers
- 73) Use a carpet sweeper, dust, or wipe off patio furniture
- 74) Clip coupons
- 75) Read aloud from labels
- 76) Put coins in a jar
- 77) Ask simple questions
- 78) Look up names in a telephone book
- 79) Count by twos
- 80) Look at magazines or books with large, colorful pictures
- 81) Read aloud from books, magazines or your loved one's hometown newspaper
- 82) Ask a friend or neighbor who has a baby or young child to visit
- 83) Have a calm pet visit
- 84) Play "dress-up"
- 85) Brush, comb or style your loved one's hair
- 86) Pamper your loved one with makeup, perfume, aftershave
- 87) Give a manicure or pedicure
- 88) Rub in scented, hypo-allergenic hand lotions

- 89) Shop from catalogues for clothes, household or fun, frivolous items
- 90) Watch television together and talk about the programs you've seen
- 91) Rent a video of an old favorite and watch it together
- 92) Take a walk or a ride
- 93) Make a birthday cake
- 94) Make a Valentine collage
- 95) Dye Easter eggs
- 96) Color paper shamrocks
- 97) Color pictures of our flag
- 98) Make a May basket
- 99) Clean out a pumpkin
- 100) String popcorn for Christmas trees
- 101) Make Holiday cards

what activities have you seen that are successful?

notes

Tab

9 R's in Alzheimer's Care

- 1) Routine will help someone with AD anticipate what to do next and what is expected of him or her. Routine sets boundaries that feel secure.
- 2) Rituals or life-long habits should be maintained. Do not try to break old habits. If the person has taken a walk after breakfast every day for thirty years, don't try to make them stop now.
- 3) Reassess physical health if there is a sudden behavior change. A person with AD will become more confused, agitated or hostile when a physical complaint develops.
- 4) Redirect or distract the person with AD. For example, if the person with AD is asking to go home, say, "In a little while, but first how about a cup of tea and a cookie?" This kind of suggestion can divert the person's thoughts, at least for a little while.
- 5) Real questions may be difficult to decipher if the person with AD has difficulty communicating. Increased agitation, for instance, could be his or her way of telling you a trip to the restroom is needed. Learn to read body language.
- 6) Reconsider the behavior. Is it really a problem, or is it just upsetting to you? Does it present a danger to the person with AD? If the person talks to his or her reflection in a mirror as if it was another person, is that a real problem? Does it please the person with AD or does it upset or frighten him or her?
- 7) Respect the person with AD. Laugh with, not at the person. Never talk about the person as if he or she is not there. And remember, the person with AD will know how you feel by your body language and tone of voice.
- 8) Reassure the person with AD often that you love and will care for him or her. A gentle pat, stroking the hair, or holding a hand all say, "I care for you."
- 9) Remember the person with AD is still a human being. Treat him or her the way you would want to be treated if you were suffering from dementia.

Summing Up

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The *Alzheimer's and Dementia Care Training Program* is funded by the state civil money penalty fund. The fund is dedicated to the improvement of care for health facility residents through educational programs targeting deficient care practices. The funds are derived from fines assessed against health facilities by the Center for Medicare and Medicaid Services for findings of deficient care practices.

Each course will be presented multiple times at various locations throughout Indiana. In the fall of 2004, the following courses will be presented:

- Fundamentals of Dementia Care for Health Facility Personnel (presented 20 sessions)
- Directing an Alzheimer's or dementia special care unit (presented 13 sessions)

In 2005, the above two courses will be repeated and the following additional courses will be offered. Each of the following courses will be presented twice at a variety of locations throughout Indiana.

- Problem Solving and Managing Behavior Issues in Dementia Care
- Effective Communication in Dementia Care
- Activities of Daily Living
- Physical Health and Safety
- Managing Daily Activities
- Strategies for Creating Better Care Environments

notes