



## **Directing an Alzheimer's/Dementia Care Unit**

### **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



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 that caregivers serve.

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

## Contributors

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## **Dementia Specific Training Program Trainers**

### **Becky Armstead, LPN**

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 trains for the National Association of Adult Day Services and serves as 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 geropsych 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 Masters 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

8-8:15 am	Welcome and Introductions
8:15-9:15 am	Module 1: Review of Dementia and Care Practices
9:15-10:15 am	Module 2: Administrative Practices
<b>10:15-10:30 am</b>	<b>Break</b>
10:30-11:30 am	Module 2, Con't: Administrative Practices
<b>11:30-12:30</b>	<b>Lunch</b>
12:30-2 pm	Module 3: Educating Staff
<b>2-2:15 pm</b>	<b>Break</b>
2:15-3:45 pm	Module 4: Reducing Deficiencies
3:45-4 pm	Evaluation and Conclusion



Perf

## F-Tags Referenced 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.	4
157	Notification of changes.	A facility must immediately inform the resident; consult with the resident's physician; and if known, notify the resident's legal representative or an interested family member when there is— (B) A change in resident rights under Federal or State law or regulations as specified in paragraph (b)(1) of this section.	1 2 4
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.	1 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.	4

F-Tag Number	Title	Description	Module
207	Equal access to quality care.	(i) A facility must establish and maintain identical policies and practices regarding policies and practices regarding transfer, discharge, and the provision of services under the State plan for all individuals regardless of source of payment; (ii) The facility may charge any amount for services furnished to non-Medicaid residents consistent with the notice requirement in 483.10(b)(5)(i) and (b)(6) describing the charges; and (iii) The State is not required to offer additional services on behalf of a resident other than services provided under the State plan.	4
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.	2 4
223	Abuse.	The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.	1 2 4

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
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.	1 2 4
225	Potential employees.	<ul style="list-style-type: none"> <li>(1) Not employ individuals who have been <ul style="list-style-type: none"> <li>a. Found guilty of abusing, neglecting, or mistreating residents by a court of law; or</li> <li>b. Have had a finding entered into the State nurse aide registry concerning abuse, neglect, mistreatment of residents or misappropriation of their property; and</li> </ul> </li> <li>(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.</li> <li>(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</li> </ul>	2

F-Tag Number	Title	Description	Module
255 Con't		<p>(4) to the State survey and certification agency).</p> <p>(5) The facility must have evidence that all alleged violations are thoroughly investigated, and must prevent further potential abuse while the investigation is in progress.</p> <p><b>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.</b></p>	
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.	1 2 3
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.	1 2 4
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.	1 2 4

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
242	Self-determination and participation.	<ul style="list-style-type: none"> <li>(1) The resident has a right to</li> <li>(2) Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care;</li> <li>(3) Interact with members of the community both inside and outside the facility; and</li> <li>(4) Make choices about aspects of his or her life in the facility that are significant to the resident</li> </ul>	1 2 4
243-244	Participation in resident and family groups.	<ul style="list-style-type: none"> <li>(1) The resident has the right to organize and participate in resident groups in the facility;</li> <li>(2) A resident's family has the right to meet in the facility with the families of other residents in the facility;</li> <li>(3) The facility must provide a resident or family group, if one exists, with private space;</li> <li>(4) Staff or visitors may attend meetings at the group's invitation</li> <li>(5) The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings;</li> <li>(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</li> </ul>	1 4

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
243-244 Con't		resident care and life in the facility.	
245	Participation in other activities.	A resident has the right to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.	4
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.	1 2 4
271-272	Resident and Comprehensive assessments.	<p>The facility must conduct initially and periodically a comprehensive, accurate, standardized reproducible assessment of each resident's functional capacity.</p> <p>(a) Admission Orders At the time each resident is admitted, the facility must have physician orders for the resident's immediate care.</p> <p>(b) Comprehensive assessments.</p> <p>(1) Resident Assessment Instrument A facility must make a comprehensive assessment of a resident's needs, using the RAI specified by the State. The assessment must include at least the following:</p> <p>(1) Identification and demographic information</p>	2

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
271-272 Con't		<ul style="list-style-type: none"> <li>(iv) Customary routine</li> <li>(v) Cognitive</li> <li>(vi) patterns</li> <li>(vii) Communication</li> <li>(viii) Vision</li> <li>(ix) Mood and behavior patterns</li> <li>(x) Psychosocial well-being</li> <li>(xi) Physical functioning and structural problems</li> <li>(xii) Continence</li> <li>(xiii) Disease diagnosis and health conditions</li> <li>(xiv) Dental and nutritional status</li> <li>(xv) Skin conditions</li> <li>(xvi) Activity pursuit</li> <li>(xvii) Medications</li> <li>(xviii) Special treatments and procedures</li> <li>(xix) Discharge potential</li> <li>(xx) Documentation of summary information regarding the additional assessment performed through the resident assessment protocols</li> </ul> <p>Documentation of participation in assessment</p>	



<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
280	Care plans.	<p>A comprehensive care plan must be</p> <ul style="list-style-type: none"> <li>(i) Developed within 7 days after the completion of the comprehensive assessment;</li> <li>(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.</li> </ul>	1 2 4
281-282	Professional standards of quality.	<p>The services provided or arranged by the facility must</p> <ul style="list-style-type: none"> <li>(i) Meet professional standards of quality and;</li> <li>(ii) Be provided by qualified persons in accordance with each resident's written plan of care</li> </ul>	2 4
285	Preadmission screening.	Preadmission screening for mentally ill individuals and individuals with mental retardation.	1

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
285 Con't		the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.	
310	Activities of daily living.	Based on the comprehensive assessment of a resident, the facility must ensure that <ul style="list-style-type: none"> <li>• A resident's abilities in activities of daily living <ol style="list-style-type: none"> <li>(1) 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"> <li>• Bathe, dress, and groom;</li> <li>• Transfer and ambulate;</li> <li>• Toilet;</li> <li>• Eat; and</li> </ul> </li> </ol> </li> </ul> Use speech, language, or other functional communication systems.	4
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 2

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
323-324	Accidents	The facility must ensure that <ul style="list-style-type: none"> <li>(1) The resident environment remains as free of accident hazards as is possible;</li> <li>(2) Each resident receives adequate supervision and assistance devices to prevent accidents.</li> </ul>	4
329	Unnecessary drugs.	Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used <ul style="list-style-type: none"> <li>(i) in excessive dose (including duplicate therapy); or</li> <li>(ii) for excessive duration; or</li> <li>(iii) without adequate monitoring; or</li> <li>(iv) without adequate indications for its use; or</li> <li>(v) in the presence of adverse consequences which indicate the dose should be reduced or discontinued; or</li> <li>(vi) any combination of the reasons above.</li> </ul>	1 2
353	Nursing services.	The facility must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care.	2 4
490	Administration.	A facility must be administered in a manner that enables it to use its resources effectively and efficiently to attain or	2

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
490 Con't		maintain the highest practicable physical, mental, and psychosocial well-being of each resident.	
495	Competency.	<p>A facility must not use any individual who has worked less than 4 months as a nurse aide in that facility unless the individual—</p> <ul style="list-style-type: none"> <li data-bbox="824 569 1105 779">(i) Is a full-time employee in a State-approved training and competency evaluation program;</li> <li data-bbox="824 779 1105 1220">(ii) Has demonstrated competence through satisfactory participation in a State-approved nurse aide training and competency evaluation program or competency evaluation program; or</li> <li data-bbox="824 1220 1105 1430">(iii) Has been deemed or determined competent as provided in 483.150 (a) and (b).</li> </ul>	2 4
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"> <li data-bbox="824 1724 1105 1875">(i) Be sufficient to ensure the continuing competence of nurse aides, but,</li> </ul>	3 4

<b>F-Tag Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
497 Con't		(ii) must be no less than 12 hours per year; (iii) 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 For nurse aides providing services to individuals with cognitive impairments, also address the care of cognitively impaired.	
498	Proficiency of nurse aids.	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.	1 2 3 4
499	Staff qualifications.	(1) The facility must employ on a full-time, part-time or consultant basis those professionals necessary to carry out the provisions of these requirements. (2) Professional staff must be licensed, certified, or registered in accordance with applicable State laws.	2

**Tab**

## **Module 1: Review of Dementia and Care Practices**

### **Objectives:**

- Define dementia and Alzheimer's disease
- Understand Alzheimer's disease progression
- Understand differences between dementia, delirium and depression
- Discuss the importance of person centered care and its implementation
- Explore the importance of stress management with family and staff

## 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

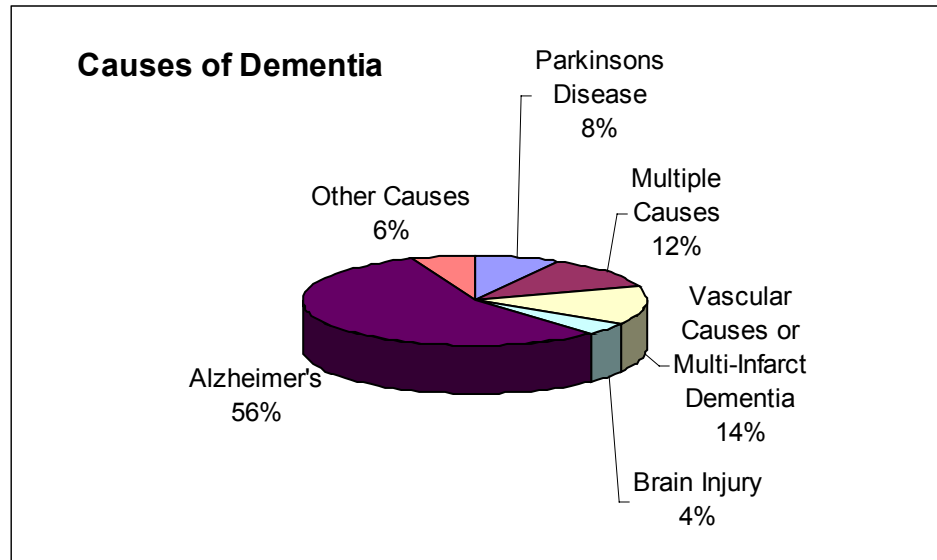
in the quiet i leave...

— 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.**

## DEMENTIA, DELIRIUM & DEPRESSION

The * areas identify hallmark signs of delirium	<b>Delirium</b>	<b>Dementia</b>	<b>Depression</b>
<b>Attention</b>	difficulty sustaining and shifting*	easily distracted	no change but may have a lack of interest
<b>Level of Consciousness</b>	decreased*; stupor*	no change	no change
<b>Mood</b>	no change	possible depression and/or anxiety	possible depression and/or anxiety
<b>Onset</b>	rapid or over several weeks	gradual	usually abrupt
<b>Course</b>	fluctuates*	progressive decline	rapid progression
<b>Thinking</b>	disorganized; delayed	impaired distraction and judgement; possible aphasia, agnosia and apraxia	negative; delayed
<b>Memory</b>	short term usually present	short term memory declines before long term memory; difficulty learning	complaints of memory deficits worse than actual deficits
<b>Perceptual Changes</b>	illusions; visual* and tactile hallucinations	possible hallucinations	none
<b>Personality</b>	no changes	altered or accentuated premorbid personality	may be irritable
<b>Sleep / Wake Cycle</b>	disturbed*	no change but may become irritable when tired and needing a nap	disturbed sleep; early morning awakening
<b>Psychomotor Activity</b>	increased; picking at sheets	pacing and 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*

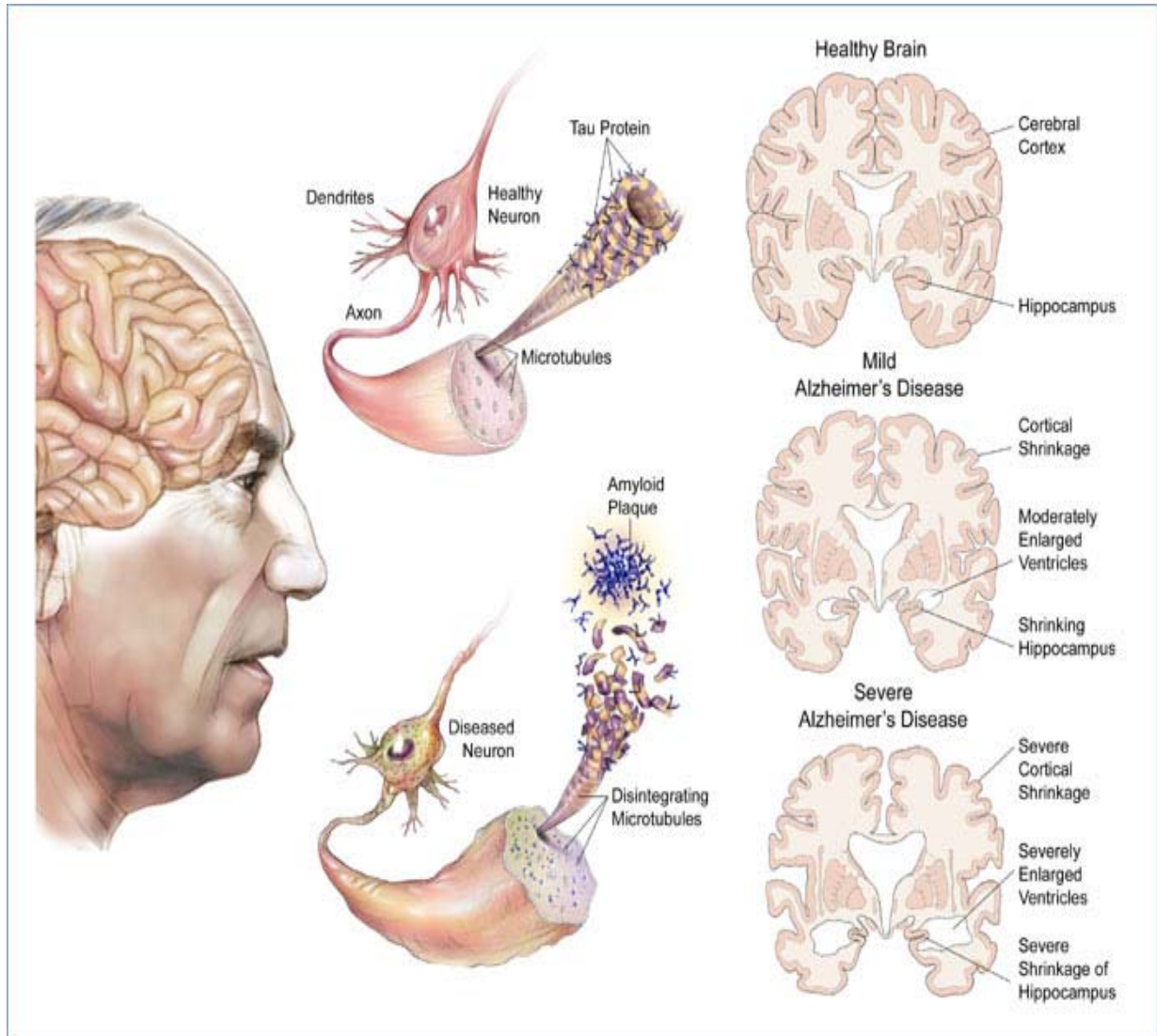
Since then, researchers have learned much about how these structures form, but they do not know exactly what role each structure plays in the loss of brain cells.

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. 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.

# Brain and Nerve Cells Change with Alzheimer's Disease



## Brain Scans

Brain with Alzheimer's

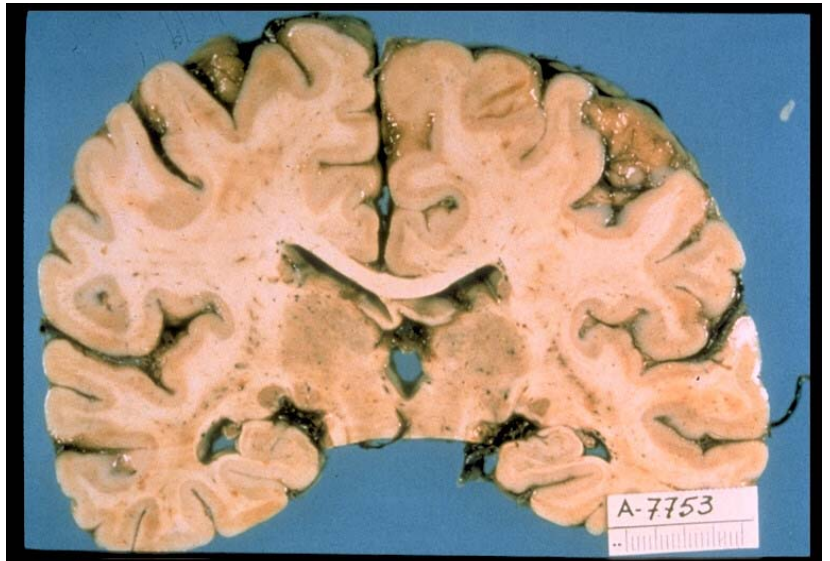


joe: sam, you know the worst thing about growing old?

sam: no, what's that?

joe: what's what?

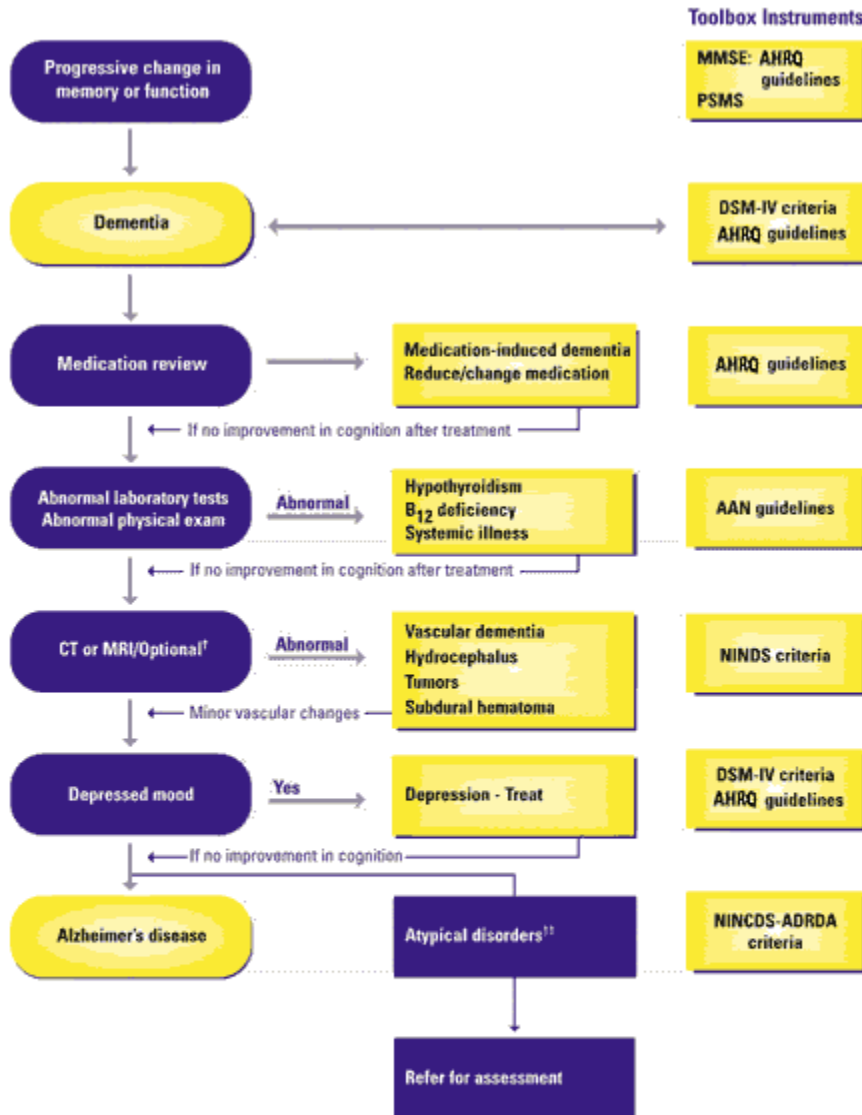
Brain without Alzheimer's



# 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.

<b>Stage 1:</b>	<b>No cognitive impairment</b>
	Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.
<b>Stage 2:</b>	<b>Very mild cognitive decline</b>
	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.
<b>Stage 3:</b>	<b>Mild cognitive decline</b>
	Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms:
	<ul style="list-style-type: none"> <li>• 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:</li> <li>• Word- or name-finding problems noticeable to family or close associates</li> <li>• Decreased ability to remember names when introduced to new people</li> <li>• Performance issues in social or work settings noticeable to family, friends, or co-workers</li> <li>• Reading a passage and retaining little material</li> <li>• Losing or misplacing a valuable object</li> <li>• Decline in ability to plan or organize</li> </ul>
<b>Stage 4:</b>	<b>Moderate cognitive decline</b> (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"> <li>• Decreased knowledge of recent occasions or current events</li> <li>• Impaired ability to perform challenging mental arithmetic-for example, to count backward from 100 by 7s</li> <li>• Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances</li> <li>• Reduced memory of personal history</li> <li>• The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations</li> </ul>

<b>Stage 5:</b>	<b>Moderately severe cognitive decline</b> (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"> <li>• 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</li> <li>• Become confused about where they are or about the date, day of the week, or season</li> <li>• Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s</li> <li>• Need help choosing proper clothing for the season or the occasion</li> <li>• Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children</li> <li>• Usually require no assistance with eating or using the toilet</li> </ul>
<b>Stage 6:</b>	<b>Severe cognitive decline</b> (Moderately severe or mid-stage Alzheimer's disease)
	<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"> <li>• Lose most awareness of recent experiences and events as well as of their surroundings</li> <li>• Recollect their personal history imperfectly, although they generally recall their own name</li> <li>• Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces</li> <li>• Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet</li> <li>• Experience disruption of their normal sleep/waking cycle</li> <li>• Need help with handling details of toileting (flushing toilet, wiping, and disposing of tissue properly)</li> <li>• Have increasing episodes of urinary or fecal incontinence</li> </ul>

	<ul style="list-style-type: none"> <li>• 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 that are not really there; or compulsive, repetitive behaviors such as hand-wringing or tissue shredding</li> <li>• Tend to wander and become lost</li> </ul>
<b>Stage 7:</b>	<b>Very severe cognitive decline</b> (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"> <li>• Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered</li> <li>• Individuals need help with eating and toileting and there is general incontinence of urine</li> <li>• 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.</li> </ul>



### 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 comorbid 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, on the other hand, 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 appears to work by regulating the activity of glutamate, one of the brain's specialized messenger chemicals involved in information processing, storage, and retrieval.**



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 descent  
 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
<b>Love</b>	“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.	
<b>Inclusion</b>	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.	
<b>Attachment</b>	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.”	

<b>Need</b>	<b>Description</b>	<b>Implementation</b>
<b>Identity</b>	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.	
<b>Occupation</b>	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.	
<b>Comfort</b>	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

**f157:**  
**notification of changes**

**f163:**  
**be fully informed**

**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**

## **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 live 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.

<b>Interaction</b>	<b>Description</b>	<b>Specific Examples</b>
<b>Recognition</b>	<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>	
<b>Negotiation</b>	<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>	
<b>Collaboration</b>	<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>	

<b>Interaction</b>	<b>Description</b>	<b>Specific Examples</b>
<b>Play</b>	<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>	
<b>Timalation</b>	<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 &amp; soothing sounds, props to provide tactile stimulation.</p>	
<b>Celebration</b>	<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>	
<b>Relaxation</b>	<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>	

<b>Interaction</b>	<b>Description</b>	<b>Specific Examples</b>
<b>Validation</b>	<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>	
<b>Holding</b>	<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>	
<b>Facilitation</b>	<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 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

## The Family Journey

### Know what families are looking for:

- Kindness and respect—Families want to know their loved one is being treated this way as well
- Looks are important—What is important to one family member may not be important to another. If the resident looks clean, cared for, and happy, the family will be more pleased with the staff
- Extras—The little things that show the staff care mean a lot

### Long term relationships

The disease process is lengthy. Sensitivity to families throughout the process is vital to a solid relationship.

Families go through many emotions throughout the disease process and many don't know how to cope with the progression. They may not know what to expect.

Be sure you and your staff know resources that can help families, such as the Alzheimer's Association. Find ways to educate and alert them to changes, like calling families in advance to notify them of a physical or cognitive change. Let them know as soon as they arrive what to expect or pieces of information that will make their visit pleasant.

Remember, grief and loss is felt while their loved one is still living. Guilt often accompanies these feelings as well.



### F-Tags

**f226:**

**staff treatment of residents**

**f243-244:**

**participation in resident and family groups**

**f280:**

**care plans**

# notes

**Tab**

## **Module 2: Administrative Practices**

### **Objectives:**

- Define the role of unit manager and its responsibilities
- Review human resources practices
- Develop a philosophy of care, including mission statement and purpose of the special care unit
- Investigate admission and discharge requirements/criteria
- Examine policies and procedures of a special care unit

# The Effective Leader

**Name of an effective leader you've worked with:**

**Traits that made this person effective:**

**Weaknesses:**

**Write an example of this leader in action**

**What did you learn from this leader?**

**How can you use this example to lead more effectively?**



F-Tags

**f240:  
quality of life**

**f241:  
dignity**

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

## **Administrative Practices**

### Identify your commitment

- Become dementia-capable—you must make conscious decisions to become dementia capable which includes:
  - Knowing the disease process
  - Knowing and sharing the types of services to help families, professionals, and those with Alzheimer's disease
- Be willing to provide dementia services even when providing services to others

### Evaluation

- Continually evaluate effectiveness and quality of care
- Identify indicators for improvement
- Encourage open communication between staff, family, and residents

### Empowering the Unit Manager position

- Challenge the process—search for opportunities and experiment
- Inspire and share vision—envision the future, enlist others to help
- Enable others to act—foster collaboration, strengthen others
- Model the way—set an example and plan small wins
- Encourage the heart—recognize contributions and celebrate accomplishments

## Ownership and leadership

Effective leaders:

- **Challenge**—Problem solve processes and strategies to accomplish work differently. Always look for more than one solution
- **Inspire**—Share your vision with the staff. Allow people to express themselves
- **Enable**—Facilitate, coach, and allow for practice
- **Model**—Many people are watching and taking cues from the leader. Be sure you are dementia-capable and demonstrating person centered care
- **Encourage**—An effective leader encourages the heart. Requires true empowerment of each individual
- **Empower**—Treat people with respect and dignity, establish trust, enable people to put their ideas into action, listen, provide praise, and give feedback.

**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*



# Sample Job Descriptions

## Licensed Vocational Nurse / Crisis Care

**Numerous Per diem, Part-time, Full-time, Days, Weekends, Flexible / 8-10-12 hour shifts available.  
IV Certification required.**

### Summary

The Licensed Vocational Nurse (LVN)- Continuous Care, under the supervision of the Registered Nurse, provides skilled nursing care to terminally ill home care patients in accordance with the treatment and plan of care dictated by patient, family, physician, and members of the interdisciplinary team. Continuous care is provided during a period of crisis and as necessary to maintain an individual at home. Continuous Care is defined as a minimum of 8 hours of care within a 24-hour period with at least 51% of the care provided by a skilled, licensed nurse.

### Education and Experience

- Must be a graduate of an approved LPN/LVN school of professional nursing, who is currently licensed as a Vocational Nurse by the State .
- Must possess a valid CPR certification. Bilingual abilities preferred.

### Knowledge / Skills

- A minimum of one year LPN/LVN experience required.
- Previous acute care, hospice or home health experience preferred.
- Must have a flexible schedule and willingness to be called onto a continuous care shift with little or no notice.
- Good knowledge of home health care principles and practices within the scope of palliative medicine.
- Familiarity with interpersonal dynamics operative within a health care team and knowledge of the dying and bereavement processes.
- Knowledge of home care principles and practices within the scope of hospice and palliative care and/or end-of-life care issues.
- Familiarity with interpersonal dynamics operative within a health care team.
- Excellent observation, verbal and written communication skills, problem-solving skills, critical thinking skills, nursing skills per competency checklist.

## **CAN / CHHA**

### **Positions available in the Hospice Home Care Program**

#### **Summary**

Provides a variety of nursing or personal hygiene services to Hospice patients as a support member of the Interdisciplinary Hospice Team, either in a patient's home or in a skilled nursing facility (SNF).

#### **Education and Experience**

- Must possess both CNA and CHHA certification in the State.
- Graduate of an approved school of professional nursing.
- Minimum of one (1) year of recent nursing or home health experience.
- Must possess a valid Driver's License and proof of automobile insurance.
- Must possess valid CPR Certification.

#### **Knowledge / Skills**

- Knowledge of home care principles and practices within the scope of hospice and palliative care and/or end-of-life care issues.
- Familiarity with interpersonal dynamics operative within a health care team.
- Excellent observation, verbal and written communication skills, problem-solving skills, critical thinking skills, nursing skills per competency checklist.

**All candidates who receive an offer for employment MUST successfully complete a health assessment and TB test/chest x-ray. Background checks and drug screenings are conducted on all potential applicants. Bilingual and/or Spanish-speaking skills desirable in ALL positions.**

## **Alzheimer's Activity Assistant**

Alzheimer's Activity Assistant—Responsible to assist in planning, organizing, and implementing a program of therapeutic activities designed to meet the social, spiritual, intellectual, emotional, educational and physical needs and interests of residents in accordance with the comprehensive resident care plan. Works closely with residents, family members, volunteers, center staff, and community representatives.

This position is a Part-time position for Friday & Saturday only; 16 hours per week. Previous experience in leading recreational activities, arts/crafts, intellectual and educational activities, community outings, etc., desired.

EDUCATION: High School Diploma with course work in recreation is desirable. Ability to read and write required.

**JOB TITLE:     DEMENTIA UNIT COORDINATOR**

**DEPARTMENT:** Administration

**SUPERVISOR:** Facility Administrator

**WORK AREA:** Dementia Care Unit

**STATEMENT OF JOB:**

Responsible for implementation of systems, coordination of nursing and leisure activities, and oversight of staff development on the Dementia Care Unit. Actively participates in admission and discharge processes on the assigned unit. Directs dementia-specific programming for residents on the assigned unit.

**QUALIFICATIONS:**

1. Must have completed, or be willing to complete, the state-mandated minimum of six hours of dementia-specific training initially and three hours annually thereafter.
2. Must have completed, or be willing to complete, the state-approved Activity Director Course.
3. Long term care management experience and /or expertise in dementia is desirable.
4. Must be able to:
  - A. Suggest changes for improvements in resident care.
  - B. Set priorities and organize assigned unit work flow.
  - C. Make decisions necessary to maintain efficient assigned unit functioning.
  - D. Communicate effectively and maintain good working relations with personnel in all facility departments, family members, other health-related individuals, and community agency personnel.
5. Must be willing to:
  - A. Keep abreast of new trends in dementia care by reading current journals and publications of the long term care industry.
  - B. Attend professional meetings, workshops, and conferences on dementia and long term care industry issues, as approved or requested by the Supervisor.

**ADMINISTRATIVE RESPONSIBILITIES:**

1. Report to work on time when scheduled.
2. Participate in the Admissions Team meetings when potential residents are reviewed, and collaborate with the team during the subsequent admissions process.

3. Responsible for the overall development and implementation of unit programming.
4. Responsible for integrating nursing and medical care services with unit programming.
5. Responsible for development and implementation of an ongoing family support program.
6. Be available to meet with families when concerns about care arise, and to offer support with respect to the grieving process.
7. Participate in staff recruitment for the unit, initial orientation, and on-going staff development programs related to persons with dementia and the unique needs of this resident population.
8. Participate in internal mandatory in-service education programs.
9. Attend external professional meetings and seminars as dictated by facility needs and prepare a summary of such programs.
10. Participate in facility committees, i.e. Interdisciplinary Care Plan Team, Behavior Management, Infection Control, and/or Quality Improvement, as requested per the Supervisor.
11. Participate in community events sponsored by groups advocating for persons with dementia.

## **RESIDENT RESPONSIBILITIES**

1. Make regular rounds on the Dementia Care Unit to ascertain the general condition of all residents.
2. Collaborate with the charge nurse regarding the condition of residents on the unit; discuss physical, psychosocial, and nutritional needs and problems; assist with identification and implementation of appropriate interventions.
3. Review resident health records and other resident-identifiable data bases, i.e., Minimum Data Set (MDS); be thoroughly familiar with physician-ordered treatment plans and comprehensive care plans, including specific behavioral goals and approaches.
4. Assist with transport of residents to dining areas, distribution of meal trays, and with feeding of residents as needed.
5. Inform the Supervisor of significant resident status changes and other related matters through written reports and/or verbal communication.
6. Assist the charge nurse in assessing the level and number of personnel assigned to the unit; make recommendations regarding such personnel where indicated for better resident care and utilization of same.
7. Be courteous and respectful to residents, families, visitors, and co-workers. Address residents by their preferred names. Respond to resident / family concerns regarding care when appropriate, or refer to the responsible administrative person.
8. Be thoroughly familiar with all unit and facility policies and procedures; implement them as written.
9. Keep other departments informed of special needs of residents; coordinate care and services with other disciplines.
10. Continuously observe the environment for conditions of cleanliness, sanitation, safety, and overall appearance to enhance optimum quality of life for residents on the unit. Report any adverse findings to the appropriate staff member for further action.
11. Perform other duties as dictated by resident care needs or as requested per the Supervisor to assure the optimum quality of resident care is delivered.

**ACTIVITY PROGRAMMING RESPONSIBILITIES:**

1. Responsible for completion of initial, quarterly, annual, and significant change activity assessments in accordance with mandatory MDS requirements. Assist with completion of MDS sections relative to activity pursuit patterns.
2. Responsible for completing documentation to support data provided in the mandatory MDS assessment process. Complete required documentation in an accurate, legible, and timely manner in accordance with professional standards of practice and federal / state regulation.
3. Responsible for composing, revising, and implementing resident care plans relative to activity programming in accordance with the mandatory MDS time frames.
4. In collaboration with the facility Activity Director, develop and post monthly activity calendars for residents residing on the Dementia Care Unit that reflect, to the degree possible, individual interests, and that allow opportunities for success based upon each resident’s current physical and cognitive abilities.
5. Supervise the conduct of, or be available to conduct, established age appropriate activity programs focusing on current physical and cognitive abilities.
6. Maintain activity attendance and participation records for each resident on the unit.

I have read this job description and fully understand the requirements set forth therein.

I hereby accept the position of Dementia Unit Coordinator and agree to abide by the requirements set forth. I will perform all functions to the best of my ability, and accept responsibility for the immediate actions of all staff under my direct supervision.

\_\_\_\_\_  
Signature, Employee

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature, Reviewer

\_\_\_\_\_  
Date

**EXPOSURE CATEGORY / BLOODBORNE PATHOGENS**

OSHA has established three (3) exposure categories of occupational exposure to infectious diseases, including HBV and HIV infections. My duties as Dementia Unit Coordinator classify me as a Category II in regard to the above fluids. I am aware of the tasks in my job description that place me in this category.

---

Signature, Employee

---

Date

---

Signature, Witness

---

Date



## **Your Job Description and Role**

**After reviewing the sample job descriptions as well as your own, consider the following:**

**What duties are not addressed in the description that need to be?**

**Where is a majority of your time spent? Does this match your unit's mission?**

**How can you strengthen your description and role?**

**How does your role interact with other team members?**

**Are families, staff, and others aware of your role?**

## Philosophy of Care

Develop a philosophy of care, including mission statement, purpose of the special care unit.

The **program philosophy** is a fundamental component of the mission statement

- Describe the purpose and intent of the special care unit
- Recognize the unique needs of those with dementia
- Identify forms of support
- Have the commitment of all staff, managers, governing bodies, administrators, etc
  
- Who program serves
  - Identify the target population—clarified in policies
  - Indicate who will benefit from the program
  - Discuss limitations of the program, who can't be served, and reasons for transfer or discharge
  
- The approach to care
  - Physical, psychosocial, spiritual, and emotional needs must be included
  - Medical care needs are consistently assessed and met
  - Care plans are developed and implemented
  - Change in condition is recognized and addressed
  - Quality care is provided
  
- Who provides care—including staff qualifications and type of training received
  
- What's "special" about special care?
  - Include information about the total care environment
  - Indicate why special care is needed for people with dementia
  - Discuss what is "special" about dementia care



### F-Tags

**f163:**

**be fully informed**

**f221/222:**

**resident behavior and facility practices**

**f223:**

**abuse**

**f224:**

**staff treatment of residents**

**f240:**

**quality of life**

**f241:**

**dignity**

**f242:**

**self determination and participation**

**f246:**

**accommodation of needs**

**f280:**

**care plans**

**f281/282:**

**professional standards of quality**

**f309:**

**quality of care**

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

--thomas carlyle

Indicators of how the care provided recognizes the unique needs of a person with dementia and their families

#### Communicating the message

- Be realistic and honest about your commitment
- Monitor words used in marketing materials that could be misleading or don't truly represent your commitment
  - When families are looking for a long term care facility, they are often not thinking of future needs or how the change in the disease process could affect the type of care needed
  - Be sure to share the commitment and a sampling of policies and procedures with families so they know exactly what to expect
  - Not every family is right for every facility, not every facility is right for every family

#### Address change in condition

- Care and treatment should reflect the resident's level of awareness and needs
- Consideration of financial changes
- Consideration of hospice services

## Sample Mission Statements

To provide a quality of life with respect, dignity and caring in a friendly, clean and non-abusive atmosphere. Woodcrest is committed to serving the needs of all of our residents.

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Our [dementia unit] is dedicated to providing persons who suffer from dementia or related disorders a safe environment, meaningful leisure activities, and assistance with personal care in a respectful and caring manner that enhances each resident's physical, mental, and psychosocial abilities.

We want to be recognized as the premiere provider of dementia care and services in the [state/region]. Our primary objective is to bring meaning, purpose, and pleasure to each resident's day through programs and services designed especially for persons with memory loss and cognitive deficits.

Our secondary objective is to promote comfort and reassurance for both our residents and their significant others. We will do this by offering support and education through internal services and external dementia support networks. We understand the unique psychosocial, spiritual, and emotional needs of persons with dementia as well as the needs of their family members and loved ones. We believe family insight, support, and participation are essential to achieving our program objectives.

Our third objective is to create opportunities for success for persons with memory loss and cognitive deficits. Our [dementia unit] is designed in a unique manner to accommodate such opportunities. We have committed extensive resources toward staff selection, training, and education necessary to promote optimum quality of life for these residents through altered care approaches.

Our [dementia unit] strives for continuous quality improvement. Program objectives have been incorporated into our quality improvement plan to assure optimum standards of professional practice are evident, and to provide the standards of care we would expect as consumers. Our success measures stem from consumer satisfaction surveys, resident outcome reviews, and internal assessment systems. Opportunities for improvement identified through this process will be molded into improvement plans to constantly enhance our programs and services.

**trust men and they will be true  
to you; treat them greatly and  
they will show themselves great.  
--[ralph waldo emerson](#)**

## **Human Resources**

The most important resource you have is your staff. Not every person is right for dementia care. The amount of satisfaction we get from doing things that make up each day goes a long way in our overall satisfaction with life. We choose to do things that we feel we have control over, feel good about, we can do well, and we do voluntarily. We do these things because it addresses our needs for security, control, inclusion, and affection.

### Characteristics of good dementia workers

Compassion  
Respect and honor  
Dependability  
Fairness  
Honesty  
Integrity  
Supportive  
Appreciation of teamwork  
Flexibility  
Creativity  
Sense of fun  
Energetic  
Warmth  
Sense of humor  
Unconditional positive regard

### Skills of good dementia care workers

Assessment  
Energy  
Problem solving  
Dementia capable communication  
Observational  
Respectful  
Conflict resolution  
Prioritizing

**Which do you find to be most important?**

**What would you add to this list?**

Recruiting needs to look beyond just filling positions, but finding the right person that can meet the philosophy of your special care unit and are dementia capable. Staff turn over and consistency influence the quality of care provided to families and residents.

- Ask current staff for recommendations
- Have a group screening where representatives from all departments interview candidates
- Interviewing should include an assessment of dementia-capable skills. Develop case examples and ask for solutions

Bell and Troxell in *The Best Friends Staff* suggest:

- Look for nontraditional candidates who can be trained
- Walk the person around the unit during the interview to see how they react
  
- Have other line staff meet with them one on one and ask for an assessment
- During the interview, hand the candidate an object and see if they can have fun with it
- Ask them to describe their own best friends. What type of words do they use?
- Share your mission and philosophy. How do they react?
- Ask for stories that show their sense of humor



#### F-Tags

**f225:**  
**potential employees**

**f353:**  
**nursing services**

**f495:**  
**competency**

**f498:**  
**proficiency of nurse aids.**

**f499:**  
**staff qualifications**

## 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

### signs of stress include:

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

### What are your signs of stress?

**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?**

**How can you help your staff cope?**



F-Tags

**f224-226:**

**staff treatment of residents**

**f223:**

**abuse**

**f240:**

**quality of life**

**f241:**

**dignity**





F-Tags

f271/272:

resident and comprehensive  
assessments

## Assessments

Preadmission/admission domains to be assessed:

**General**—age, gender, language, occupation, education

**Medical**—Diagnoses, history, physical status

**Functional**—Ability to perform ADL's, sensory status, motor skills

**Emotional**—Mood, coping status, sources of pleasure, comfort, pain

**Social**—Significant relationships, ability to interact

**Cognitive**—Ability to comprehend, perceive, express, reminisce

**Behavioral**—Daily schedules and routines, strengths, problematic behaviors

**Special needs**—glasses, hearing aids, walker, wheel chair, diet

**Special interests**—Life aspirations, hobbies, preferences

**Habits**—Daily routines, sleeping habits, bathing routines, food

**Interventions**—Responses to techniques and strategies used with success in the past

**Talents**—Past and current skills and gifts

**Religion**—Preferences, routines, rituals

- Ascertain the validity of the diagnoses by looking to see if a complete, multi-disciplinary approach was taken, including blood and urine tests, brain scan, mental status exam, and language testing
- Determine if depression may be occurring (either disguised as dementia or in conjunction with dementia)
- Treatable disorder that is causing confusion (delirium)
- Dementia other than Alzheimer's disease

Level of functioning

- Discern the compatibility of the person's needs and abilities with those of the residents in the special care unit
- Balance of current levels of care needed by other residents
- Establish a baseline of function to identify changes in the future
- Social needs, preferences, behaviors, and medical needs
  - Determine compatibility of individual with the special care unit's philosophy of care
  - Maintain a balance of social needs and personalities among existing participants
- Family wishes and needs to ensure that the special care unit can provide for the family as well as the resident
  - Provide a tour
  - Fully inform of philosophy, types of programs offered, costs, security
- Advanced directives

**my mother**

**she lays there alone  
on her hospital bed  
in a nightgown and a diaper  
adult size or such  
knotted fingers on her hands  
covering her eyes  
shielding her confusion  
from whatever recognition remains  
with a smile of distant  
unfamiliarity  
masking the lies of her  
now diminished memory  
keeping her enclosed  
with restraints of austerity  
and breaking through with fits  
of uncalled-for levity**

**my mother has alzheimer's disease**

***– by joan price, in honor of her  
mother***

# Special Care Unit Assessment

**ADL Self Performance—Code for resident’s performance over all shifts during the last 7 days, not including set up.**

**Complete 1-7 with the following score**

**0—Independent—No help or oversight**

**1—Supervision—Oversight, encouragement, or cueing provided**

**2—Minimal—Resident highly involved in activity; received physical help in guided maneuvering of limbs or other non-weight bearing assistance**

**3—Moderate/Extensive—While resident performed part of the activity, over the last 7 day period, help of the following types provided three or more times:**

**Weight bearing support**

**Fully staff performance during part, but not all, of the last seven days**

**4—Total dependence—Full staff performance of an activity during entire 7 days**

**On section 8-12 indicate by checking all that apply. If two or more areas are italics, a team evaluation must be completed to determine if the resident continues to meet the established criteria. Bold italics indicate the resident no longer meets the criteria.**

<b>FUNCTIONAL STATUS</b>	<b>Date</b>	<b>Score</b>	<b>Date</b>	<b>Score</b>	<b>Date</b>	<b>Score</b>	<b>Date</b>	<b>Score</b>
<b>DRESSING</b>								
Forgets to change clothing—needs reminders								
Needs clothing laid out, then can dress self								
<i>Needs to be dressed, but can assist</i>								
<i>Requires frequent clothing changes per staff assist</i>								
<i>Requires moderate assistance</i>								
<b>GROOMING</b>								
Needs assist or verbal cueing to be shaved								

Able to wash self with set up								
Requires step by step instruction								
Independent or needs cue with oral care								
<i>Requires moderate assist</i>								
<b>BATHING</b>								
Sponge bath without assist								
Requires assist to shower/bath								
<i>Requires moderate assist with shower/bathing</i>								
<b>EATING AND NUTRITION</b>								
Needs tray set up								
Needs to have food cut and identified, able to feed self								
Needs prompting throughout meal								
Improper use of utensils, uses hands, steals food, fed at times								
<i>Needs fed all meals by staff</i>								
<b>MOTOR COORDINATION</b>								
Occasionally requires assistance of handrails								
Uses assistive device—walker, can, crutch or temp								
Requires minimum stand by assist								
Unsteady gait, shuffles feet								
Unsteady all of the time								
Frequent falls								

<i>Able to stand for transfers only, unable to ambulate</i>								
Able to walk: (check one)								
150 feet or more with or without assistive								
75 feet or less								
<b>CONTINENCY— URINE/FECES</b>								
Occasional urinary inc/dribbling								
Has inc. episodes 3x or less per week								
Asks to go—needs cue to locate toilet								
Needs to be reminded to go, but can go alone								
Needs to be taken to bathroom regularly to maintain dryness								
<i>Does not know when he/she needs to go</i>								
<i>Total inc.</i>								
<b>PAD USAGE</b>								
Undergarment or small pad used								
Puts soiled pads in inappropriate places to be reused								
Needs assist to change undergarment regularly								
<i>Wears briefs—frequent changes by staff</i>								
<b>SPATIAL ORIENTATION</b>								
Oriented to immediate area only								

May need occasional reorientation to a room								
Has need for structured or secured environment								
Looses or hides things								
Disorientated to place, cannot locate own room								
Unaware of safety needs								
Wandering aimlessly								
<b><i>Totally unaware</i></b>								
<b>ATTENTION</b>								
Disoriented to time, place, person								
Responsive, needs reminders for dates and events								
Able to follow directions								
Attention span becoming short								
Loses train of thought in mid-sentence								
<i>Slow to respond, if at all</i>								
<b><i>No longer aware of surroundings</i></b>								
<b>SOCIAL INTERACTIONS</b>								
Participates in interactions, but is a follower								
Needs emotional support								
Withdrawn								
<b><i>Observer only</i></b>								
<b><i>Disturbs others with behaviors</i></b>								

<b><i>Frequently unresponsive to others</i></b>								
<b>COMMUNICATION</b>								
Needs prompting and cueing								
Aware of what he/she wants to communicate, but words don't come out appropriately								
Repeats self, aware of repetition								
Circumlocutions, white lies								
Less aware of mistakes								
Parrot words, severe vocabulary loss								
<i>Unable to communicate</i>								
<b>MEDICATION AND TREATMENT</b>								
Needs medications dispensed per nursing staff								
Requires frequent observation due to medication								
Medications must be crushed								
Frequently refuses meds								
<b><i>Inability to meet medication needs</i></b>								

**Resident's Name**

**Room #**

**Physician:**

## **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

**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— 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.

they were put, often prompts these suspicions. 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 use of sponge baths? 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**

## Problem Solving Behaviors

<b>Related to:</b>	<b>Specific Issue</b>	<b>Problem Solving Steps</b>
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

<b>Related to:</b>	<b>Specific Issue</b>	<b>Problem Solving Steps</b>
	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.

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

## **Policies and Procedures**

- Mission Statement
- Philosophy of Care
- Dementia-Capable Program Components, Objectives, and Expected Outcomes
- Dementia Care Bill of Rights
- Person Centered Care Delivery
- Dementia-Capable Activity Programming
- Environmental Modifications
- Family Support Program
- Admission / Discharge Criteria
- Medical Evaluation
- Resident Assessment Process
- Interdisciplinary Care Planning Process
- Non-Pharmacological Behavioral Interventions
- Hydration and Nutrition Program
- End-of-Life Decisions
- Role of Dementia Unit Coordinator
- Dementia-Capable Staff Development Program
- Quality Assessment and Improvement Process

The following may duplicate facility-wide Policy / Procedure if they include adaptation for cognitively impaired residents:

- Abuse Prevention, Investigation, and Reporting
- Accident Prevention – Elopement
- Accident Prevention – Falls
- Advance Directives
- Aspiration Risk
- Grievance Process
- Incontinence Care Protocol
- Incontinence Rehabilitation
- Maintaining a Restraint-Free Environment
- Pain Assessment
- Palliative Care
- Physician and Family Notification of Change of Condition
- Prevention and Treatment of Pressure Sores
- Privacy and Confidentiality
- Psychoactive Drugs
- Restorative Nursing
- State Reportable Unusual Occurrences
- Transfer and Discharge Notification

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

**--sir william osler**

# notes

**Tab**



## Module 3: Educating Staff

### Objectives:

- Define basic principles of adult education, including needs of adult learners
- Identify types of audiences within a facility and types of education services desired
- Examine techniques to assess for types of education needed for by department, individual, and task
- Understand materials provided for educational support
- Explore and assess potential internal and external resources for educational services

## Educating Adults

Often, adults who attend educational opportunities have rearranged their schedules and made a great effort to attend, even in long term care settings. We need to be respectful and considerate of the learner. We need to provide an encouraging and empowering environment as well as information that they have a desire to learn or will be beneficial in some way. It is important that educators understand some basic concepts of adult education. Adults have unique and individual needs, and it is important that we do our best to serve everyone's learning styles.

Malcome Knowles, a world renowned adult educator, described adult learners as being self-directed, generally deriving only positive benefits from the educational event, are ready to learn, volunteer to attend and participate in programs, are task or problem centered, and are motivated to learn. It is important that the facilitator view the learners in this manner--that they are motivated to learn and want information to help them in their lives.

The **educator** is the organizer, guiding learning through helping participants understand their own experiences and how new information can aid them. The educational event enhances personal growth and self-actualization.

Dean suggests that educators consider their own skills, identifying specific concepts that need to be explored, understanding the context, and learning about the learners as a process for designing instruction in *Designing Instruction for Adult Learners*.

By understanding the learners, instructors' capabilities, the context, and information to be focused on, the educator can determine if they are the "right" person for the "job."



F-Tags

**f498:**  
**proficiency of nurse aides**

**i'd rather one should walk  
with me that tell me the  
way.  
--edgar a. guest**

## **Successful Learning**

**Ensure successful learning--**Be prepared with extra information or be available to answer questions one on one before or after the program. This helps to ensure that everyone learns something that will help them. Provide quality instruction and constructive feedback.

**Make the program safe and interesting--**The first impression is important! Be sure the environment is appropriate for learning and that material is presented in a non-threatening way.

**Make the learning goals clear, and stick to them--**By clarifying what you will be covering, it will help cut down on the amount of distractions.

**Clarify the criteria of evaluation--**We have few tools to measure the success of programs. Be sure to explain the evaluation early in the program so that participants can fill it in during the program, yielding a more accurate evaluation.

**Promote self-empowerment--**Provide opportunity and resources for participants to direct their own learning and attitudes.

**Emphasize the felt needs of the learners--**Be aware of what the participants are feeling, their interests, and needs. Make the abstract apply to the felt needs expressed.

**Provide a variety of learning techniques--**Some people are visual learners, while others learn from listening. Include different techniques.

## Types of Learners

In order to teach effectively, it is important to recognize the difference in learning styles. Each individual has a unique way of understanding information, processing it, and applying the new information to themselves and their specific situation.

There are several assessments available for adults to assess their personal learning style. However, trainers/educators don't always have the luxury of administering an assessment to each adult learner they work with. Below is a chart that explains some common learning styles that assists in understanding how learning is achieved.

<b>Style</b>	<b>Characteristics</b>
Navigators	Focused learners that plan learning and follow it. Prefer teachers that maintain a structured environment. Are easily frustrated and impatient with relaxed instruction.
Monitors	Aware of their progress as learners and monitor their learning process. Monitoring involves testing assumptions and evaluating to find results. Stay focused by setting logistics and avoiding distractions. Do not like brainstorming and experimenting.
Critical Thinkers	Rely on reflective thinking (involves "higher order" thinking skills). Prefer environments that allow for experience and practice. Like assessments that are open-ended.
Engagers	Love to learn with feeling, and do best when actively engaged. Want a relationship with the educator. Tend to have lowest test scores. Need teachers who are focused on the whole rather than on assessments.
Networkers	Want human resources. Discussion with professionals and experts is blended with social and political process of learning. Like opinions, want support, to listen, and networking. Looking for instruction that shares experience through story telling and learning that is fun.

The research done on this model (Conti and Kolody, 1995-1997) suggests that labels can help us identify what types of learners are in the educational setting and how to respond in order to have the best learning events possible. Each learner is unique and should be treated as so.

We can begin to assess what types of learners are in the educational event beforehand by administering a simple needs assessment or during the event by watching feedback and monitoring interactions. An educator will most likely not have all of the same type of learner, but activities, lectures, assessments, etc. can be modified so that there is variety for each learner.

## Ways to Teach

Good presentations or educational events are designed to meet the needs of the learners. For some, a corporation may determine that all employees need to have a training on a new policy, for others, a learner may seek out a course that teaches them about a new hobby.

Since we know that a variety of learning techniques satisfy more learners in our program, we need to consider what types of techniques to use. Learning techniques include things such as:

- Hands-on activities—experiments, case studies, evaluating examples
- Lecture
- Small group activities
- Brainstorming
- Group discussion
- Reflection
- Self-directed learning (such as learning from books or independent study)
- Role play
- Movies or other media

Rosemary Caffarella suggests ten factors in deciding how an educator should decide what types of instructional techniques should be used.

Factor	Comments	Factor	Comments
Learning Objectives	What is the focus? New knowledge? Developing skills? Problem solving? Changing attitudes?	Content	What type of information is being shared? How can it best be communicated?
Instructors	Are the instructors capable and comfortable with the learning techniques?	Technique Characteristic	What can be done with the technique? How many times do you have to do it?
Learners	How many? What type of learners? What are their expectations? Will they participate?	Variety	Are you offering a variety of techniques to make sure everyone learns?
Context	Why are the learners at the event?	Logistical constraints	Are there costs to using the techniques? Do you have appropriate resources?
Transfer of Learning	What can be done to make sure that the information is learned and can be applied?	Time	Does the technique fit into the time allotted?

## Techniques for Assessment

As mentioned earlier, catering to the learner's needs and respecting their desires is the most important element to designing an educational event. You must recognize that you are part of the audience, having a strong hand in the potential success of the event. The more information you can gather in advance, the more you can cater to the audience by preplanning instructional techniques and content.

By not assessing needs and the audience as a whole, you will not be able to deliver meaningful, understandable messages. Determining needs can be achieved in a variety of ways, and is sometimes as simple as looking at the sign in sheet (and asking for key information on the sign in sheet), looking around the room, or asking someone who has worked with the group before about the group dynamics. Regardless of how in-depth you are able to assess, always consider the following:

- Age group
- Gender
- Ethnicity
- Education
- Religions
- Socio-economic status
- Group membership (does the audience belong to a specific group? What is associated with the group?)
- Voluntary versus captive audiences
- Size and location of educational event

It may be helpful to analyze the organization, person, and task that are part of the need for training.

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

<b>To Analyze</b>	<b>Definition</b>	<b>Consider</b>
Organization	Determining context	Appropriateness of training, resources, support from managers and peers
Person	Who needs to attend	Determine readiness, performance deficiencies result from a lack of information, skill, or motivation, overall desire to learn
Task	Content of event	Identify knowledge, skills, and behaviors that need to be emphasized

Information can be gathered through observation, questionnaires, records, interviews, or informal gatherings. Once the educator gathers this information, he or she can begin to determine learning objectives, content, instructional techniques, organization, and visual aids that will assist in delivering the messages that will inform and cause learners to act.

### Motivating to Learn

Self-efficacy is also essential to building a good program. By showing learners the benefits of attending, they begin to believe in the content and the desire to learn will grow. Promotional materials and information about the event should stress that the event will help learners improve in some capacity, not to point out that the learners are incompetent. Consider using Maslow's hierarchy of needs and appeal to the needs that match the learners. Other tips include:

- Provide positive feedback throughout the training
- Speak positively about the event
- Provide time to practice and apply new information

Allow for discovery of information through reflective, self-directed, and experiential learning

## On-site Preparation

A room that is poorly lit, seats that are cluttered, and audio-visual aids that can't be seen by all can lead to learners not being able to hear or listen to your presentation. By spending time assessing and organizing the physical environment, the learners will have a better chance of receiving and understanding information presented. The following is a checklist of items to look for.

### Meeting Room

- Lighting is adequate
- Ventilation is good
- Temperature is comfortable for the majority
- Layout of the room is adequate for the instructional techniques you've planned
- The room is clean and organized
- Refreshments are set up

### Instructors and Program Staff

- All staff are clear of their roles during the event
- All staff materials are clearly laid out and easily accessible

### Equipment

- Each piece works as it should
- The equipment is placed in a position so that everyone can see it
- Back up parts and extension cords are available

### Materials

- Learners have a schedule or agenda
- Copies of information sent out in advance are available
- There are enough handouts for all learners

### After the Program

- Evaluations are collected
- The room is cleaned up
  - Conduct a staff debriefing



### F-Tags

**f226:**  
**staff treatment of residents**

**f497:**  
**regular in-service education**



# notes

**Tab**



## **Fundamentals of Dementia Care for Health Facility Personnel**

### **Overview**

The eight-hour Fundamentals of Dementia Care for Health Facility Personnel is designed for non-medical companions, personal care assistants, Qualified Medical Assistants, dietary staff, office staff, Certified Nursing Assistants, activity assistants, environmental services, and other staff members that work with those with dementia on a regular basis and provide direct service.

The purpose of this course is to provide basic information about Alzheimer's disease and related dementias, best care practices, and assisting families. State regulations and reducing deficiencies will be a part of each section as well as the information provided below.

### **Delivering the Training**

The following pages contain an outline of the lecture component of training. It is important to tailor the contents of the lecture with hands-on activities, such as role play, demonstration, video examples, case studies, group discussion, and small group work for your audience.

Please attend the Fundamentals of Dementia Care for Health Care Personnel to experience activities and the lecture presented in the manner intended by the Alzheimer's Association.

### **Training Outline**

#### **Module 1:**

#### **Understanding Memory Loss**

**45 minutes**

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

#### **Module 2:**

#### **Person Centered Care**

**1 hour, 15 minutes**

- Understand person centered care and its characteristics
- Identify strategies for implementing person centered care
- Discuss important steps in taking care of the professional caregiver

**Module 3:  
Communication**

**1 hour**

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

**Module 4:  
Understanding Behaviors**

**1 hour, 15 minutes**

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

**Module 5:  
Activities of Daily Living**

**1 hour**

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

**Module 6:  
Families**

**45 minutes**

- Empathize with feelings that persons with AD 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 for a long-term relationship with the resident and family

## F-TAGS Used in This Manual

<b>F-TAG Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
<b>154</b>	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
<b>163</b>	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
<b>164</b>	Privacy and confidentiality	The resident has a right to personal privacy and confidentiality of his or 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
<b>221-222</b>	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
<b>223</b>	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
<b>224-226</b>	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
<b>225</b>	Potential employees.	<p>(1) Not employ individuals who have been</p> <ol style="list-style-type: none"> <li>a. Found guilty of abusing, neglecting, or mistreating residents by a court of law; or</li> <li>b. Have had a finding entered into the State nurse aide registry concerning abuse, neglect, mistreatment of residents or misappropriation of their property; and</li> </ol> <p>(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.</p> <p>(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).</p> <p>(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.</p> <p>(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.</p>	2
<b>240</b>	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
<b>241</b>	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

<b>F-TAG Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
<b>242</b>	Self-determination and participation.	The resident has a right to (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
<b>243-244</b>	Participation in resident and family groups.	(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
<b>246</b>	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

<b>F-TAG Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
<b>280</b>	Care plans.	A comprehensive care plan must be (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
<b>285</b>	Preadmission screening.	Preadmission screening for mentally ill individuals and individuals with mental retardation.	1
<b>309</b>	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
<b>310</b>	Activities of daily living.	Based on the comprehensive assessment of a resident, the facility must ensure that (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"> <li>• Bathe, dress, and groom;</li> <li>• Transfer and ambulate;</li> <li>• Toilet;</li> <li>• Eat; and</li> <li>• Use speech, language, or other functional communication systems.</li> </ul>	5
<b>316</b>	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
<b>319</b>	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



<b>F-TAG Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
<b>320</b>	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
<b>323-324</b>	Accidents	The facility must ensure that (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

<b>F-TAG Number</b>	<b>Title</b>	<b>Description</b>	<b>Module</b>
<b>329</b>	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"> <li>(i) in excessive dose (including duplicate therapy); or</li> <li>(ii) for excessive duration; or</li> <li>(iii) without adequate monitoring; or</li> <li>(iv) without adequate indications for its use; or</li> <li>(v) in the presence of adverse consequences which indicate the dose should be reduced or discontinued; or</li> <li>(vi) any combination of the reasons above.</li> </ul>	1
<b>497</b>	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"> <li>(i) Be sufficient to ensure the continuing competence of nurse aides, but, must be no less than 12 hours per year;</li> <li>(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</li> <li>(iii) For nurse aides providing services to individuals with cognitive impairments, also address the care of cognitively impaired.</li> </ul>	2
<b>498</b>	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

<p style="text-align: center;">✓ F-Tags</p> <p><b>F498:</b> Proficiency of nurse aids</p>	<p><b>Understanding Memory Loss (45 minutes)</b></p> <p><b>Objectives:</b></p> <ul style="list-style-type: none"> <li>• <b>Define of dementia and Alzheimer’s disease</b></li> <li>• <b>Understand stages of the disease and the expectations, including behaviors</b></li> <li>• <b>Learn about current medications and treatments</b></li> </ul>
	<p>We will begin with an overview of Alzheimer’s disease and dementia. By understanding the disease process, we can more fully understand behaviors, communication strategies, personal care, and care philosophies.</p> <p>The topics for this session are:</p> <ul style="list-style-type: none"> <li>• Definition of dementia and Alzheimer’s disease</li> <li>• Stages of the disease and the expectations, including behaviors</li> <li>• Current medications and treatment</li> </ul> <ul style="list-style-type: none"> <li>• Define dementia and Alzheimer’s disease <ul style="list-style-type: none"> <li>○ Dementia is not a disease but a disease process. It is an umbrella term that refers to a group of symptoms <ul style="list-style-type: none"> <li>• Progressive decline in cognitive function</li> <li>• Intellectual functions such as thinking, remembering, and reasoning are altered</li> <li>• Severe enough to affect everyday life</li> <li>• A person must have memory loss and loss in cognitive function</li> </ul> </li> <li>○ Over 170 illnesses cause irreversible dementia, including:</li> </ul> </li> </ul>

	<ul style="list-style-type: none"><li>• HIV-AIDS</li><li>• Vascular Dementia</li><li>• Lewy Body Disease</li><li>• Parkinson's disease</li><li>• Huntington's disease</li><li>• Alzheimer's disease</li></ul> <p>○ There are some reversible (or treatable) forms of dementia, including:</p> <ul style="list-style-type: none"><li>• Thyroid disorders</li><li>• Drug interactions</li><li>• Dehydration</li><li>• Depression</li></ul> <p>○ Delirium and depression can look like dementia and can coexist with dementia</p> <ul style="list-style-type: none"><li>• Delirium is an acute onset, can be treated</li><li>• An altered level of consciousness occurs with delirium</li><li>• Depression may be gradual in onset, can be treated. There may be reduced memory with depression.</li><li>• Look for signs of depression<ul style="list-style-type: none"><li>• Loss of initiative</li><li>• Feelings of worthlessness</li><li>• Low self-esteem</li><li>• Decreased or increased sleep</li><li>• Appetite changes</li><li>• Crying</li><li>• Thoughts of death</li></ul></li><li>• See medical professional if you see anything unusual</li></ul>
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**F-Tags**

**F285:** Preadmission screening

**F319:** Mental and psychosocial adjustments

- Alzheimer's disease is the most common form of irreversible dementia
  - Nearly 70% of all dementias are Alzheimer's disease
  - Over 4.5 million Americans have Alzheimer's disease
  - It is estimated that 60% of all nursing home residents have Alzheimer's disease
  - It is a disease, not part of the normal aging process
  
- Alzheimer's disease affects these specific areas severely enough to affect everyday life:
  - Language (naming things)
  - Personal care
  - Memory (short term in the early stages, long term memory in the later stages)
  - Judgment and reason
  - Psychomotor speed
  
- Alzheimer's disease is not a normal part of aging
  - With normal aging, some changes occur:
    - Learning new information may take longer
    - May be difficult to concentrate and filter out noise

- Three specific changes happen in the brain with Alzheimer's disease:
  - Plaques and tangles
  - Brain chemicals—specific neurotransmitters decrease, which are the chemicals that send messages from cell to cell
    - Neurons in the brain communicate with each other. Plaques gets in the way of the communication processes.
  
- What does Alzheimer's disease look like in the brain?
  - Shrinkage (atrophy)
  - Plaques and tangles
  - Neuron (cell) death
    - Risk factors:
      - Age
        - Youngest documented case is thought to be at age 17
        - 5% of population between ages 55-65 have Alzheimer's disease
        - 33-50% of people over age 85 have Alzheimer's disease
      - Head injury
        - Severe, such as comma, head trauma
      - Down's Syndrome
        - It is assumed that 100% of people with Down's will develop Alzheimer's

	<ul style="list-style-type: none"><li>○ The only way to know for sure that someone has Alzheimer's disease is with an autopsy. A multidisciplinary approach leads to a diagnosis that is 80-90% accurate. The diagnostic process involves:<ul style="list-style-type: none"><li>● Blood and urine tests</li><li>● MRI or other brain scan</li><li>● Mental status exam</li><li>● Hearing/visual exams</li><li>● Physical exam</li><li>● Psychological testing</li><li>● Interview with family members or caregiver</li><li>● Neuropsychological testing</li></ul></li> <li>● Identify stages of the disease and expectations, including behaviors<ul style="list-style-type: none"><li>○ Understand that stages are only a point of reference<ul style="list-style-type: none"><li>● Generally, there are three stages of Alzheimer's disease: early, middle, and severe.</li> <li>● There is not a clear-cut boundary for each</li> <li>● The "average" length of the disease is 8 years, but may last up to 20 years</li> <li>● Early:<ul style="list-style-type: none"><li>● Person might recognize something is wrong</li><li>● Can still function independently, but needs reminders</li></ul></li></ul></li></ul></li></ul>
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	<ul style="list-style-type: none"><li>• Memory loss is apparent</li><li>• Daily routines become more difficult</li><li>• Concentration becomes difficult</li> <li>• Middle:<ul style="list-style-type: none"><li>• Needs 24-hour supervision and much direction</li><li>• May need some hands-on care</li><li>• Memory loss and confusions increase</li> <li>• Sleep disturbances may begin to develop</li><li>• The person may get lost easily</li><li>• Outbursts of anger, suspiciousness, and anxiety may begin to appear</li><li>• Change in personality</li></ul></li> <li>• Late:<ul style="list-style-type: none"><li>• Severe confusion</li><li>• May lose most or all of functional skills</li><li>• Needs hands-on care for most personal care</li><li>• Walking, independent eating, and other motor skills may be lost</li><li>• Bladder and bowel may incontinence occur</li><li>• Swallowing problems may develop</li><li>• Meaningful communication may disappears</li><li>• The person may not recognize self or family</li></ul></li></ul>
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- Areas of the brain, especially areas controlling behaviors and daily functioning, are affected during the progression
  - Changes in cognition:
    - Memory
    - Learning
    - Language
    - Praxic functions
    - Visuospatial abilities
    - Abstract thinking
    - Psychomotor speeds
  
  - Changes in behavior:
    - Communication skills deteriorate
    - Safety becomes an issue due to loss of memory, judgment, and reasoning skills
    - Personal care skills deteriorate
    - Development of behaviors due to increasing confusion and lapses in clarity and comfort
    - May have hallucinations or delusions
  
  - Changes in emotion:
    - Emotional responses become disregulated and disorganized
    - Apathy appears (loss of energy and willingness)
    - Lability—moods can change, usually in reaction to changes in the immediate situation

	<ul style="list-style-type: none"><li>○ Determine realistic expectations<ul style="list-style-type: none"><li>● Since the disease is progressive, we need to anticipate that what a person could do one day they may not be able to do the next</li><li>● Remember that the person with Alzheimer's disease had a previous life—family, hopes, dreams, etc. and that those feelings and needs still exist.</li><li>● Depression and delirium or a co-morbid illness may also occur, and the person with Alzheimer's disease may not be able to tell you. Be the advocate for the personal well-being of your resident.</li></ul></li><li>● Understand current medications<ul style="list-style-type: none"><li>○ There is no cure for Alzheimer's disease<ul style="list-style-type: none"><li>● Current medications may prolong cognitive function longer</li><li>● Because of side effects and other factors, not all people with Alzheimer's disease take medications</li></ul></li><li>○ Cholinesterase inhibitors<ul style="list-style-type: none"><li>● Prevents breakdown of chemical that assists in cell communication</li><li>● Slows down progression of disease<ul style="list-style-type: none"><li>● Cognex</li><li>● Aricept</li><li>● Exelon</li><li>● Reminyl</li></ul></li></ul></li></ul></li></ul>
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<p style="text-align: center;">✓</p> <p style="text-align: center;"><b>F-Tags</b></p> <p><b>F222:</b> Chemical restraints</p> <p><b>F329:</b> Unnecessary drugs</p>	<ul style="list-style-type: none"> <li>○ Glutamate receptors <ul style="list-style-type: none"> <li>• Blocks random signals from stimulating nerve cells while allowing the real signals to get through</li> <li>• Works on a different chemical than the others</li> <li>• Also helps slow down the progression <ul style="list-style-type: none"> <li>• Namenda</li> </ul> </li> </ul> </li>   <li>○ Expectations of the medications <ul style="list-style-type: none"> <li>• May only have results for a few months or a few years</li>   <li>• Sometimes no change is a result</li>   <li>• Many people have reactions to the drug, especially gastrointestinal</li>   <li>• Namenda may be used in conjunction with a cholinesterase inhibitor <ul style="list-style-type: none"> <li>• Other drugs may be used to treat depression or behaviors, but the medical advisor must be very careful not to prescribe drugs that will increase confusion or will interact with other medications leading to adverse reactions</li> </ul> </li> </ul> </li> </ul>
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Summing Up:

- Dementia is the umbrella term for a group of symptoms, specifically a progressive decline in cognitive function severe enough to affect everyday life
- Alzheimer's disease is the most common form of dementia accounting for 70% of all dementias
- Stages are used as a point of reference only
- We need to have realistic expectations of what a person can and can't do because of the disease process and help them continue to do what they still can
- Some medications are available to help those who have dementia, but they are not a cure and may be limited in the amount of time they are effective

<p style="text-align: center;">✓ F-Tags</p> <p><b>F240:</b> Quality of life  <b>F241:</b> Dignity  <b>F242:</b> Self determination and participation  <b>F319:</b> Mental and psychosocial adjustments  <b>F223:</b> Abuse  <b>F246:</b> Accommodation of needs  <b>F309:</b> Quality of care</p>	<p><b>Person Centered Care (1 hour, 15 minutes)</b></p> <p><b>Objectives:</b></p> <ul style="list-style-type: none"> <li>• <b>Understand person centered care and its characteristics</b></li> <li>• <b>Identify strategies for implementing person centered care</b></li> <li>• <b>Find ways to take care of the professional caregiver</b></li> </ul>
	<p>The topics for this session are</p> <ul style="list-style-type: none"> <li>• Understanding person centered care and its characteristics</li> <li>• Identifying strategies for implementing person centered care</li> <li>• Find ways to take care of the professional caregiver</li> </ul> <ul style="list-style-type: none"> <li>• Understand person centered care and its characteristics <ul style="list-style-type: none"> <li>○ Person centered care is truly putting the person first <ul style="list-style-type: none"> <li>• Consider all needs, not just medical or physical</li> </ul> </li> <li>○ Define the philosophy of person centered care <ul style="list-style-type: none"> <li>• Behaviors are a desire for communication on the part of the person with dementia <ul style="list-style-type: none"> <li>• Behaviors are an opportunity for communication on the part of care partners</li> </ul> </li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• We must maintain and uphold the value of the person regardless of his/her level of dementia <ul style="list-style-type: none"> <li>• We must consider attempts to provide the core psychological needs (love, comfort, attachment, inclusion, occupation, identity)</li> </ul> </li>   <li>• Promote positive health</li>   <li>• All action is meaningful</li>   <li>• Our work must contain elements of positive person work</li>   <p style="text-align: center;"><i>“Dementia Reconsidered”</i>, Tom Kitwood, Buckingham, University Press 1998</p>   <li>○ Core psychological needs of a person with dementia and/or disability must be met to provide quality care. <ul style="list-style-type: none"> <li>• <b>Love</b> – “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.</li>   <li>• <b>Inclusion</b> – Total acceptance of the person and your efforts to make them feel included and connected to other members of the group will actually make</li> </ul> </li> </ul>
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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.”
- **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



### F-Tags

**F157:** Notification of changes

**F163:** Be fully informed

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.
  
- Identify strategies for implementing person centered care
  - Determine specific ways each individual can contribute to person centered care practices
    - 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.
  
    - **Recognition:** Both the care receiver and care giver are acknowledged as separate persons affirmed in their uniqueness.
      - 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.
  
  - **Negotiation:** 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.

- Personal preferences honored. Alternative activity choices are routinely provided. Some choice provided on issues of food preference.
- **Collaboration:** 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.
  - Build on abilities. Not “doing to” but “with”. Collaborate on environment of care.
- **Play:** 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.
  - Accepting spontaneity. Not childish but perhaps childlike. Adults may need permission to play.
- **Timalation:** A fancy word to

	<p>describe appealing to your senses and meeting those primal needs without the intervention of intellectual understanding. For example, massage and aromatherapy.</p> <ul style="list-style-type: none"> <li>• Aromatherapy, hand massage, pleasing &amp; soothing sounds, props to provide tactile stimulation.</li> </ul> <ul style="list-style-type: none"> <li>• <b>Celebration:</b> 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. <ul style="list-style-type: none"> <li>• “Share” our celebrations rather than “create” celebrations.</li> </ul> </li> <li>• <b>Relaxation:</b> Of all forms of interaction, this has the lowest level of intensity and often the slowest pace. <ul style="list-style-type: none"> <li>• Respecting individuality and offering a variety of relaxation avenues, i.e., TV, relaxation tapes, guided imagery, storytelling, quiet/alone time.</li> </ul> </li> <li>• <b>Validation:</b> 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.</li> </ul>
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- 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.
  
- **Holding:** 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.
  - Demonstrating consistent behavior acceptance. Give individual recognition (hugs, thank-you’s). Get rid of terms like “bibs”, “diapers” as they reduce dignity for adults.
  
- **Facilitation:** 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.
  - 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.”

	<ul style="list-style-type: none"><li>○ Examine specific examples of implementing person centered care<ul style="list-style-type: none"><li>● Understand what reality is for them</li><li>● See past their disability and find their strengths</li><li>● Relate to them as one human being to another</li><li>● Help them to hold on to and express their individual identities</li><li>● Help them to make the most of their strengths and abilities</li><li>● Help them to be as independent as possible while depending on us for any assistance they need</li><li>● Enable them to make choices and take reasonable risks</li><li>● Help to compensate for the effects of their dementing illness</li><li>● Help them to feel included and stay part of the social world</li><li>● Help them to feel respected, valued, and wanted</li><li>● Help them to feel safe and secure</li><li>● Support them while they express their feelings</li></ul></li></ul>
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	<ul style="list-style-type: none"><li>• Make an effort to understand their communication and help them to understand us</li><li>• Treat them as we would wish to be treated ourselves</li></ul> <ul style="list-style-type: none"><li>• Discuss important steps in taking care of the professional caregiver<ul style="list-style-type: none"><li>○ Person centered care won't work unless the caregiver is also being taken care of</li><li>○ Dementia care is a unique opportunity that isn't right for everyone<ul style="list-style-type: none"><li>• In dementia care, being there is often more important than what we do for a person</li><li>• We have the opportunity to make the present day meaningful for a person who can no longer look forward to a better tomorrow</li><li>• Unique demands are also part of caregiving—the person will get worse regardless of the type of care; the person may not recognize you; the person may not be able to give you feedback</li></ul></li></ul></li></ul>
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<p style="text-align: center;">✓ F-Tags</p> <p><b>F223:</b> Abuse  <b>F224:</b> Staff treatment of residents  <b>F225:</b> Potential employees  <b>F240:</b> Quality of life  <b>F241:</b> Dignity  <b>F497:</b> Regular in-service education</p>	<ul style="list-style-type: none"> <li>• Identify sources of motivation and encouragement <ul style="list-style-type: none"> <li>○ Staff input <ul style="list-style-type: none"> <li>• Care plans are a work in progress</li> </ul> </li> <li>○ Visualize <ul style="list-style-type: none"> <li>• You can be successful! Sometimes it helps to visualize success</li> <li>• Use visualization to find a peaceful place</li> </ul> </li> <li>○ Compliment others and be willing to accept compliments <ul style="list-style-type: none"> <li>• We're often quick to "blow off" compliments. We should receive them and acknowledge what we've done well</li> <li>• Others need compliments, too!</li> </ul> </li> <li>○ Use of the "buddy" system <ul style="list-style-type: none"> <li>• Find a buddy that can relieve you when you truly need a break</li> <li>• Be willing to do the same in return</li> <li>• Don't take advantage—if you abuse the privilege, your buddy won't be there for you for very long</li> </ul> </li> <li>○ Banish gossip!</li> <li>○ Have fun</li> </ul> </li> </ul>
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	<ul style="list-style-type: none"><li>○ Don't be afraid to ask for help. It is a sign of strength, not weakness</li> <li>○ Identify how stress relates to abuse and neglect</li> <li>● 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.</li> <li>● Distress affects dementia care because when professional caregivers are stressed out<ul style="list-style-type: none"><li>● The quality of care is reduced</li><li>● The caregiver's quality of life is reduced</li><li>● The caregiver will eventually experience burnout</li><li>● Distress and strong feelings have a physical impact</li></ul></li> <li>● Signs of stress include<ul style="list-style-type: none"><li>● Too little or too much sleep</li><li>● Nightmares</li><li>● Fatigue</li><li>● Headaches</li><li>● Diarrhea/Constipation</li><li>● Backaches</li><li>● Pain in joint/muscles</li><li>● Frequent accidents</li></ul></li></ul>
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	<ul style="list-style-type: none"><li>• Coping is key to your health and to providing quality care<ul style="list-style-type: none"><li>• Prevention is key<ul style="list-style-type: none"><li>• Learn about dementia so that you can understand the residents' behaviors and needs<ul style="list-style-type: none"><li>• Have realistic expectations of what residents can and can't do</li><li>• Accept your mistakes and be gentle with yourself</li><li>• Accept and enjoy your success</li></ul></li></ul></li><li>• Cope effectively when you do become distressed<ul style="list-style-type: none"><li>• Become aware that you are distressed</li><li>• Physical signs such as unsettled stomach and headaches</li><li>• Feelings that you attempt to push down such as guilt, grief, and anger</li></ul></li><li>• Find support among friends<ul style="list-style-type: none"><li>• Allow for expression of feelings</li><li>• Share similar experiences</li><li>• Praise and offer encouragement</li><li>• Take time out</li><li>• Go to a quiet place, even if just for a moment</li><li>• Take breaks when they are scheduled—think and talk about happy things</li></ul></li></ul></li></ul>
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	<ul style="list-style-type: none"> <li>• Change the pace of your work periodically</li> <li>• Away from work <ul style="list-style-type: none"> <li>• On your way home, focus on one good thing that happened, not just on problems</li> <li>• Talk about feelings with a family member or friend who will listen and not judge</li> <li>• Participate in activities that are completely different than caregiving</li> <li>• Exercise!</li> <li>• Relax</li> <li>• Don't be afraid to ask for help</li> </ul> </li> </ul> <p>Summing up:</p> <ul style="list-style-type: none"> <li>▪ Person centered care is a care philosophy that puts the person first, promoting good health, positive relationships, and tending to a person's entire well-being</li> <li>▪ Strategies such as understanding a person's social history, developing a relationship, and taking care of your own needs will help us achieve person centered care</li> <li>▪ With dementia care, we have a unique opportunity to have a long-term relationship with our residents and their families</li> <li>▪ Taking care of yourself is just as important as taking care of your residents</li> </ul>
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	<p><b>Communication (1 hour)</b></p> <p><b>Objectives:</b></p> <ul style="list-style-type: none"> <li>• <b>Discuss the impact of verbal and non-verbal communication</b></li> <li>• <b>Examine and demonstrate techniques for promoting meaningful communication with persons with dementia</b></li> <li>• <b>Understand the correct use of validation and reality orientation</b></li> </ul>
	<p><b>Introduction</b></p> <ul style="list-style-type: none"> <li>• The most important thing we can do is to make contact with people with dementia as one human being to another. Every task we do with a person with dementia should also be an opportunity for communication</li> <li>• Every moment of contact we have with a person with dementia is significant and can have a positive or negative effect</li> <li>• An exchange with a person with dementia can have value even if it does not make sense to us</li> <li>• Non-verbal interaction is often the most important communication channel for people with dementia</li> <li>• Always assume that a person with dementia understands, at some level, any comments made in their presence</li> <li>• Good listening is a fundamental communication skill</li> </ul>

The topics for this session are:

- 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
  
- Importance of communication
  - Good communication is essential to dementia care. Good communication will
    - Bolster self-worth
    - Validate feelings
    - Provide meaningful activities
    - Stimulate memories
    - Calm and reassure
  
- Discuss the impact of verbal and non-verbal communication with persons with dementia
  - Because Alzheimer's disease damages the brain that controls communication, we cannot rely on just speech to convey messages
    - Each person is unique and will be affected differently
    - Word-finding abilities usually decrease in the early stages
    - Memory loss causes people to repeat questions or phrases because they cannot remember they've already said it or they don't remember the answer

	<ul style="list-style-type: none"> <li>• Difficulty following conversations— Distractions are often overwhelming</li> <li>• Automatic speech is still available (repeating a phrase they've said all of their life over and over)</li> <li>• Swear words—No one knows why swear words are retained, but remember it is the disease that causes this</li> <li>• Reading—Often a person can read but is unable to understand the meaning of the words</li> <li>• Eventually all forms of communication will fail</li> <li>• Behaviors become a form of communication</li> </ul> <ul style="list-style-type: none"> <li>○ Identify verbal versus non-verbal communication <ul style="list-style-type: none"> <li>• Verbal communication is the words we use and how we use them <ul style="list-style-type: none"> <li>• Tone</li> <li>• Pitch</li> <li>• Rate</li> <li>• Pause</li> </ul> </li> <li>• Non-verbal communication are the actions that communication messages <ul style="list-style-type: none"> <li>• Gestures</li> <li>• Facial expressions</li> <li>• Posture</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"><li>• The importance of non-verbal communication is high<ul style="list-style-type: none"><li>• Communication is only 10% verbal. How we say something is more important than what we say</li><li>• Ability to understand—people with Alzheimer’s disease understand non-verbal communication long after written and spoken words have been forgotten</li></ul></li> <li>• Examine and demonstrate techniques for promoting meaningful communication with persons with dementia<ul style="list-style-type: none"><li>○ Non-verbal strategies for effective communication<ul style="list-style-type: none"><li>• Remember that your mood will be mirrored</li> <li>• Approach the person from the front so that you don’t startle</li> <li>• Establish eye contact</li> <li>• Speak at eye level whenever possible</li> <li>• Use gentle touch to calm or reassure a person</li> <li>• Point or demonstrate where you want the person to go or what you want them to do</li></ul></li></ul></li></ul>
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**F-Tags**  
F223: Abuse

- 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

	<ul style="list-style-type: none"> <li>• Don't argue</li>   <li>• Understand the correct use of validation and reality orientation <ul style="list-style-type: none"> <li>○ Discuss the importance of validation (The Feil Method) <ul style="list-style-type: none"> <li>• Acknowledging another person's feelings is called validation</li>   <li>• There is a reason behind all behaviors, even in the most confused person</li>   <li>• Ignoring emotions that produce behaviors won't modify the behavior. In fact, often it makes it worse</li> </ul> </li>   <li>○ Identify ways to validate <ul style="list-style-type: none"> <li>• <b>Become part of the person's reality</b>—regardless of when or where that might be</li>   <li>• <b>Acceptance</b>—to accept someone's reality doesn't mean that we have to lie or agree with something that isn't true</li>   <li>• <b>Feelings into words</b>—Naming the feeling behind the words isn't the same as agreeing</li>   <li>• <b>Acknowledgement</b>—Acknowledging feelings will help the caregiver react sensitively and gently to the needs of the resident</li> </ul> </li> </ul> </li> </ul>
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<p style="text-align: center;">✓ F-Tags</p> <p><b>F154:</b> Right to be fully informed</p>	<ul style="list-style-type: none"> <li>○ Understand the repercussions of reality orientation <ul style="list-style-type: none"> <li>● Reality orientation is the process of attempting to orient a person to the current day, time, and place <ul style="list-style-type: none"> <li>● In the early stages, a person might prefer to be oriented to reality, but short explanations should be used</li> <li>● When it becomes stressful to a person with Alzheimer’s disease to hear this type of information, reality orientation should no longer be used</li> <li>● As the disease progresses, the ability to understand new information decreases and becomes frustrating</li> <li>● Reality becomes based on past memories because that is the area of the brain that is still functioning</li> </ul> </li> <li>● Unwanted effects <ul style="list-style-type: none"> <li>● Hostility— reminding a person of what they can no longer do can lead to anger and aggression</li> <li>● Loss of trust—Questioning someone’s reasoning may sound like questioning someone’s credibility or accusing them of lying</li> <li>● Unnecessary grief—How many times would you want to hear that your loved one is dead?</li> </ul> </li> </ul> </li> </ul>
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- Understand the use of therapeutic fibbing
  - 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 used to be helpful or kind to someone with dementia
  - Should only be used when absolutely necessary, look for other ways to calm and support the resident, such as redirection

Summing up:

- Good communication is vital to providing quality care. We must use verbal and non-verbal communication strategies in order to communicate and listen well
- Non-verbal communication is understood well past the point of verbal communication not being understood. Non-verbal communication is generally more important and says more than verbal communication
- Using short, simple sentences at a time that are free from distraction is usually the best way to communicate

<p style="text-align: center;">✓ F-Tags</p> <p>F221/222: Resident behavior and facility practices F223: Abuse F224: Staff treatment of residents</p>	<p><b>Understanding Behaviors (1 hour, 15 minutes)</b> <b>Objectives:</b></p> <ul style="list-style-type: none"> <li>• <b>Understand how and why behaviors become challenging</b></li> <li>• <b>Name ways to prevent behaviors</b></li> <li>• <b>Demonstrate techniques for responding to challenging behaviors</b></li> <li>• <b>List emotions a person with dementia is likely to experience and how to respond to them</b></li> </ul>
	<p><b>Introduction</b></p> <ul style="list-style-type: none"> <li>• The person centered care approach moves beyond disease-focused thinking that stresses disabilities and personal deficits to ability based care</li> <li>• This challenges us to look at the root cause of behaviors. We do not ignore the person's anxiety but learn new responses to it</li> <li>• Persons with dementia may <ul style="list-style-type: none"> <li>• Interpret personal care as an assault</li> <li>• Be expressing frustration with care staff giving too much or not enough help</li> <li>• Express frustration with their disabilities</li> <li>• Express anger at restraints</li> </ul> </li> </ul> <p>The topics for this section are</p> <ul style="list-style-type: none"> <li>• Understanding how and why behaviors become challenging</li> <li>• Name ways to prevent behaviors</li> <li>• Demonstrate techniques for responding to challenging behaviors</li> <li>• List emotions a person with dementia is likely to experience and how to respond to them</li> </ul>

	<ul style="list-style-type: none"><li>• List emotions a person with dementia is likely to experience and how to respond to them<ul style="list-style-type: none"><li>○ Understand basic human emotions<ul style="list-style-type: none"><li>• It is a basic emotion need to express emotions</li><li>• There are four basic human emotions:<ul style="list-style-type: none"><li>• Joy (pleasure, love, happiness, sexuality)</li><li>• Anger (rage, hate, displeasure)</li><li>• Fear (guilt, shame, anxiety)</li><li>• Sadness (misery, grief)</li></ul></li><li>• People with Alzheimer’s disease often experience all of these, but feelings of fear, anger, loneliness, embarrassment, worthlessness, and isolation are most common</li><li>• Many believe that people retain their emotional link to the world regardless of how close to the end of life a person is</li></ul></li><li>○ Responding to feelings<ul style="list-style-type: none"><li>• Enter the other person’s reality</li><li>• Look for the feelings behind the words or behaviors</li><li>• Empathize—walk in their shoes</li><li>• Be non-judgmental</li><li>• Respect their needs—treat the person as a valued human being</li></ul></li></ul></li></ul>
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	<ul style="list-style-type: none"> <li>• Communicate comfort, warmth, and praise</li> <li>• Your emotions will be mirrored—monitor yourself</li> <li>• Smile!</li> <li>• Put the person’s feelings into words</li> <li>• Allow for negative feelings—Provide comfort, and don’t brush them off or disagree</li> <li>• Reminisce—Allows for use of the memory that is still there</li> <li>• Share feelings—It’s okay to talk about how you feel</li> </ul> <ul style="list-style-type: none"> <li>• Understand how and why behaviors become challenging <ul style="list-style-type: none"> <li>○ Why behaviors occur <ul style="list-style-type: none"> <li>• Alzheimer’s disease affects the area of the brain that controls emotions making one more prone to acting out</li> <li>• When people are confused they are more likely to feel anxious, afraid, suspicious, and angry</li> <li>• The nature of caregiving is very personal, intimate, and intrusive which can lead to behaviors</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>○ The impact of the approach of the caregiver can determine if a person with Alzheimer’s disease will exhibit behaviors <ul style="list-style-type: none"> <li>• Behaviors are part of the disease process, not a personal attack</li> <li>• Behaviors are a form of communication</li> <li>• Caregivers should attempt to find the meaning behind each behavior</li> <li>• Look to a person’s social history for potential clues</li> <li>• We need to avoid labeling and looking at behaviors as being problematic</li> </ul> </li>   <li>○ Problem solve behaviors as it may relate to: <ul style="list-style-type: none"> <li>• The task <ul style="list-style-type: none"> <li>• <b>Task is too complicated</b>— Breaking down tasks into small, concrete steps is an effective technique that enables a person with Alzheimer’s disease to succeed</li> <li>• <b>Too many steps combined</b>— Combining too many steps together may increase confusion, eventually leading to failure of the task</li> <li>• <b>Tasks not modified for increasing impairments</b>—As the person’s functioning declines, more help is needed. Also, consider other impairment such as declining vision or hearing</li> <li>• <b>Task is unfamiliar</b>—People with Alzheimer’s disease gradually</li> </ul> </li> </ul> </li> </ul>
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lose their ability to learn new things. Focus on activities that the person can still do

- The environment
  - **Environment is 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 cues**—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 environment**—People with Alzheimer’s disease need a routine and daily structure to feel secure. This reduces stress, but be willing to be flexible

	<ul style="list-style-type: none"> <li>• <b>Unfamiliar environment</b>—New environments can be confusing, focus on activities the person is used to</li>   <li>• Physical health <ul style="list-style-type: none"> <li>• <b>Effects of medication</b>—People with Alzheimer’s disease are vulnerable to over-medication or to reactions from drug combinations</li> <li>• <b>Impaired vision or hearing</b>—Both of these can affect a person’s ability to understand what’s being said</li> <li>• <b>Acute illness</b>—Urinary tract infections, pneumonia, and fever may increase confusion</li> <li>• <b>Chronic illness</b>—Angina, congestive heart failure, or diabetes can affect a person’s mood or level of functioning</li> <li>• <b>Dehydration</b>—Many people with dementia do not get enough fluids because they no longer recognize the sensation of thirst or they forget to drink</li> <li>• <b>Constipation</b>—This can be very uncomfortable and lead to bowel impaction</li> <li>• <b>Depression</b>—Many symptoms of depression resemble those of dementia. In addition, it is common for people with dementia to have depression</li> <li>• <b>Fatigue</b>—Disrupted sleep patterns can cause angry or agitated behaviors</li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• <b>Physical discomfort</b>—If immediate needs are not being met, then the person experiences discomfort</li>   <li>• Miscommunication <ul style="list-style-type: none"> <li>• 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</li> </ul> </li>   <li>○ Assessing Behaviors <ul style="list-style-type: none"> <li>• Look for the “Eleven W’s” of Challenging Behaviors <ul style="list-style-type: none"> <li>• <b>Who</b> actually has the challenging behavior—the person or the caregiver?</li> <li>• <b>What</b> is the specific problem or behavior?</li> <li>• <b>Why</b> does it need to be addressed? Who is it hurting/bothering?</li> <li>• <b>What</b> happens just before the behavior (triggers)?</li> <li>• <b>Where</b> does the behavior occur (environment)?</li> <li>• <b>What</b> does the behavior mean?</li> <li>• <b>When</b> does the behavior occur (time, task)?</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• <b>What</b> is the time, frequency, and pattern of the behavior?</li> <li>• <b>Who</b> is around when the behavior occurs?</li> <li>• <b>What</b> is the outcome of the behavior?</li> <li>• <b>What</b> is the DESIRED change or outcome of the behavior?</li> </ul> <ul style="list-style-type: none"> <li>• Name ways to prevent behaviors <ul style="list-style-type: none"> <li>○ 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</li> <li>○ Techniques for prevention <ul style="list-style-type: none"> <li>• <b>Diversion or distraction</b>—moving or shifting the person’s attention from one stimulus to another</li> <li>• <b>Removal</b>—separating the person from the situation or stimulus</li> <li>• <b>Redirection</b>—moving or shifting energy from one activity to another</li> <li>• <b>Task breakdown</b>—separating an activity into smaller and simpler steps</li> <li>• <b>Stimulus control</b>—provide limited choices</li> <li>• <b>Environmental manipulation</b>—control noise level, lighting, and temperature</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• <b>Reassurance</b>—provide a sense of safety and security</li> <li>• <b>Setting limits</b>—take control of the situation and not allow certain actions or activities to happen</li> </ul> <ul style="list-style-type: none"> <li>• Demonstrate techniques for responding to challenging behaviors <ul style="list-style-type: none"> <li>○ Anxiety/agitation <ul style="list-style-type: none"> <li>• General unrest, uneasiness, or apprehension. These may include hostile actions such as shouting, screaming, and object throwing</li> <li>• Response to misinterpretation of environmental factors including other people</li> </ul> </li> <li>○ Problematic wandering <ul style="list-style-type: none"> <li>• 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</li> <li>• Leaving an area that creates discomfort, expending excess energy, discomfort, exhibiting lifelong patterns of work or time schedule</li> </ul> </li> </ul> </li> </ul>
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- 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

Summing Up:

- Behaviors are a form of communication. Each behavior needs to be carefully examined for the message it may be sending
  
- We need to not judge or label people based on their behaviors. Instead of looking at each behavior as a problem, we need to find the characteristic about the behavior that is a strength
  
- Preventing behaviors is knowing the triggers. Look at the task, environment, physical health, and potential miscommunication for potential triggers

<p style="text-align: center;">✓ F-Tags</p> <p><b>F164:</b> Privacy and confidentiality  <b>F240:</b> Quality of life  <b>F241:</b> Dignity  <b>F242:</b> Self determination and participation  <b>F223:</b> Abuse  <b>F224:</b> Staff treatment of residents  <b>F246:</b> Accommodation of needs  <b>F309:</b> Quality of care  <b>F310:</b> Activities of daily living  <b>F323/324:</b> Accidents</p>	<p><b>Activities of Daily Living (1 hour)</b>  <b>Objectives:</b></p> <ul style="list-style-type: none"> <li>○ Identify causes for resistance to ADLs</li> <li>○ Describe strategies that promote participation in personal care</li> <li>○ Identify and demonstrate possible techniques for managing ADLs</li> <li>○ Identify signs of abuse and neglect</li> </ul> <hr/> <p>The topics for this session are</p> <ul style="list-style-type: none"> <li>○ Identify causes for resistance to ADLs</li> <li>○ Describe strategies that promote participation in personal care</li> <li>○ Identify and demonstrate possible techniques for managing ADLs</li> <li>○ Identify signs of abuse and neglect</li> </ul> <ul style="list-style-type: none"> <li>● Identify causes for resistance to ADLs <ul style="list-style-type: none"> <li>○ Affects of Alzheimer’s disease on the brain: <ul style="list-style-type: none"> <li>● Memory loss <ul style="list-style-type: none"> <li>▪ Forgets to complete an ADL</li> <li>▪ Forgets that an ADL has been completed</li> </ul> </li> <li>● Decreased attention span <ul style="list-style-type: none"> <li>▪ Loss of interest due to distraction during ADL</li> <li>▪ Inability to place tasks in a logical order</li> <li>▪ Unable to remain still</li> </ul> </li> <li>● Impaired judgment <ul style="list-style-type: none"> <li>▪ Lack of regard to safety</li> <li>▪ Privacy may or may not be an issue</li> <li>▪ Disorientation</li> </ul> </li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• Forgetting people, time, and place</li> <li>• Inability to understand relationship with caregiver</li> <li>• Emotional upset</li> <li>• Frustration</li> </ul> <ul style="list-style-type: none"> <li>▪ Loss of ability to communicate <ul style="list-style-type: none"> <li>• Inability to reason or rationalize</li> <li>• Unable to ask questions or understand answers</li> </ul> </li> <li>▪ Difficulty with motor skills <ul style="list-style-type: none"> <li>• Unsteady gait</li> <li>• Increased falls</li> <li>• Inability to coordinate movements</li> </ul> </li> </ul> <ul style="list-style-type: none"> <li>○ Discuss the need for sensitivity during personal care <ul style="list-style-type: none"> <li>• Personal care is very private, and can seem intrusive</li> <li>• History of abuse that personal care may trigger</li> </ul> </li> </ul> <ul style="list-style-type: none"> <li>• Describe strategies that promote participation in personal care <ul style="list-style-type: none"> <li>○ It is your responsibility to anticipate problems or events <ul style="list-style-type: none"> <li>▪ If you can anticipate, you can successfully prevent problems or events</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"><li>▪ If you cannot anticipate the problems, you should have an established method for correcting problems or events as they occur</li> <li>○ We need to provide a routine, but remain flexible<ul style="list-style-type: none"><li>▪ Consistency leads to success</li></ul></li> <li>○ General steps<ul style="list-style-type: none"><li>• Establish rapport with the person before attempting the ADL</li> <li>• Always talk in a calm voice no matter what the situation</li> <li>• Do not attempt to use reason or logic</li> <li>• Do not rush—allow enough time for the person to complete all or parts of it without being hurried</li> <li>• Avoid arguing—<b>“he can resist if you don’t insist”</b></li> <li>• Focus on abilities and encourage independence</li></ul></li> <li>○ Approach<ul style="list-style-type: none"><li>• Knock before entering and announce yourself</li> <li>• Close the door while assisting with personal care</li></ul></li></ul>
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	<ul style="list-style-type: none"><li>• Keep other residents and staff members from entering while assisting with personal care</li><li>• Allow the person to feel in control by offering simple choices</li><li>• Encourage the person to do as much for himself or herself as possible<ul style="list-style-type: none"><li>▪ Give help before the person becomes frustrated</li><li>▪ Never take over an activity because the person is slow, this takes away from remaining abilities and independence</li></ul></li><li>• Praise for small success<ul style="list-style-type: none"><li>▪ Give compliments as soon as they are earned, do not wait to reward positive behavior</li><li>▪ Give encouragement freely and frequently</li></ul></li><li>• Provide for privacy<ul style="list-style-type: none"><li>▪ Respect the person's level of modesty</li><li>▪ Remember that their generational needs may be different than yours</li></ul></li><li>• Do not keep an individual waiting<ul style="list-style-type: none"><li>▪ Have all items ready in advance</li><li>▪ Leaving the room creates a distraction and leads to inability to comply</li></ul></li><li>• Demonstrate what you want done<ul style="list-style-type: none"><li>▪ Help the person start the task</li><li>▪ Break the task into small steps</li></ul></li></ul>
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<p style="text-align: center;">✓ F-Tags</p> <p><b>F316:</b> Incontinence</p>	<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>▪ Sequence the steps to help simplify the task</li> </ul> </li> <li>• Stop when frustration occurs <ul style="list-style-type: none"> <li>▪ Do not continue once frustration is apparent</li> <li>▪ Stop and try again later</li> <li>▪ Have someone else try</li> </ul> </li> <li>• Make sure the environment is appropriate for personal care <ul style="list-style-type: none"> <li>▪ Well lit</li> <li>▪ Clean</li> <li>▪ Free of clutter</li> <li>▪ Warm</li> <li>▪ Soothing music that the resident would enjoy</li> </ul> </li> <li>• Find out preferences from person's family <ul style="list-style-type: none"> <li>▪ Did the person usually take a bath or shower?</li> <li>▪ What time of day did he or she bathe?</li> </ul> </li> <li>• Identify and demonstrate possible techniques for managing ADLs <ul style="list-style-type: none"> <li>○ Dressing <ul style="list-style-type: none"> <li>• In the early stages, use gentle reminders when clothing needs to be changed; this can be embarrassing</li> <li>• Lay out clothes for a person to who can dress independently</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• Limit choices on clothing options</li> <li>• Encourage the joy of “dressing up.” Offer jewelry, hair ribbons, etc</li> <li>• 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. These can be soothing.</li> </ul> <ul style="list-style-type: none"> <li>○ Bathing <ul style="list-style-type: none"> <li>• Keep the routine consistent</li> <li>• Ensure as much privacy as possible</li> <li>• Ensure adequate lighting</li> <li>• In the middle stages <ul style="list-style-type: none"> <li>▪ Have bath water and supplies ready</li> <li>▪ Separate bathing from hair washing</li> <li>▪ Remember that a daily bath may not be necessary</li> <li>▪ Keep the bathroom as homelike as possible</li> <li>▪ Keep distractions to a minimum</li> </ul> </li> <li>• In the late stages <ul style="list-style-type: none"> <li>▪ Gently coach the person during each step</li> <li>▪ Using cupping—put the person’s hand over yours</li> </ul> </li> </ul> </li> <li>○ Toileting <ul style="list-style-type: none"> <li>• People can suffer from incontinence for a variety of reasons <ul style="list-style-type: none"> <li>▪ Medical conditions like urinary tract infections</li> <li>▪ Stress can cause leakage</li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"><li>▪ Bladder irritants like coffee and citrus juice</li><li>▪ Inadequate hydration—lack of fluid will make the urine more concentrated causing irritation to the bladder that can lead to incontinence</li><li>▪ Medications—some drugs as well as drug interactions may affect the bladder</li></ul> <ul style="list-style-type: none"><li>• Evaluate incontinence<ul style="list-style-type: none"><li>• When do accidents occur?<ul style="list-style-type: none"><li>○ If only wetting at night, decide if waking him or her up in the night is appropriate</li><li>○ Establish the person’s typical toileting pattern and try to stick to it</li></ul></li><li>• Did the incontinence begin suddenly?<ul style="list-style-type: none"><li>○ A physical illness or side effects from medications should be considered</li><li>○ Look for increased confusion as it may be a sign of an acute illness or stroke</li></ul></li><li>• Where is the person voiding?<ul style="list-style-type: none"><li>○ If the person is on the way to the restroom when the accident occurs, this suggests stress incontinence</li><li>○ If the person is voiding in places like wastebaskets and closets, make sure the restroom is clearly marked and unobstructed</li></ul></li></ul></li></ul>
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- 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
  - 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

	<ul style="list-style-type: none"><li>• Pleasurable experience<ul style="list-style-type: none"><li>• Make eating a social activity as well as a pleasurable sensory experience</li></ul></li><li>• Independence<ul style="list-style-type: none"><li>• It has been said that eating is the hardest activity to give up to another person.</li></ul></li><li>▪ Action steps<ul style="list-style-type: none"><li>• Ensure adequate fluid intake<ul style="list-style-type: none"><li>• Offer liquids every two hours</li><li>• Look for creative ways to offer liquids, such as as a part of an activity or items such as Popsicles and ice cream</li><li>• 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</li></ul></li><li>• Respond to appetite changes; the person may have a loss of appetite or forget that they have eaten</li><li>• Reduce the effects of declining perceptual abilities. Use plates and placemats that are solid colors and contrast with each other</li><li>• Limit choices and allow for focus by offering one food at a time and</li></ul></li></ul>
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	<p>one utensil</p> <ul style="list-style-type: none"> <li>• Reassure the resident calmly when the person ask questions or is concerned</li> <li>• Monitor agitation <ul style="list-style-type: none"> <li>• Constant pacing burns extra calories</li> <li>• Make sure physical needs are taken care of</li> <li>• Serve the agitated person first</li> </ul> </li> <li>• Decrease mealtime confusion <ul style="list-style-type: none"> <li>• Minimize distraction</li> <li>• Limit number of people to a table to three or four</li> </ul> </li> <li>• Sit opposite of the person if you need to monitor swallowing or watch for pocketing of food</li> <li>• Sit beside a person if you are guiding their hands for self feeding</li> <li>• Join them!</li> </ul> <p>○ Sleeping</p> <ul style="list-style-type: none"> <li>• Sleeping becomes a problem because of: <ul style="list-style-type: none"> <li>• Age</li> <li>• Internal clocks being disturb by the disease process</li> <li>• Lack of exercise</li> <li>• Pain, medication, and depression</li> </ul> </li> </ul>
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	<ul style="list-style-type: none"> <li>• Sleep disturbances are part of the disease process</li> <li>• Action steps <ul style="list-style-type: none"> <li>• Keep a log of sleep behaviors</li> <li>• Look for side effects from medications</li> <li>• Evaluate for depression</li> <li>• Decrease caffeine consumption</li> <li>• Increase physical activity</li> <li>• Relieve pain at night</li> <li>• Offer a bedtime snack</li> <li>• Avoid upsetting activities in the evening</li> <li>• Choose a sufficient lighting level</li> </ul> </li> <li>▪ Even when all of these steps are taken, some individuals will still want to be up at night <ul style="list-style-type: none"> <li>• 24 hour care is our obligation</li> <li>• Offer activities that are soothing</li> </ul> </li> <li>▪ When the person does get up at night <ul style="list-style-type: none"> <li>• Speak softly</li> <li>• Gently reassure if there has been a nightmare</li> <li>• Reassure him or her that he or she is safe and help him or her get back to bed</li> </ul> </li> <li>○ Identify signs of abuse and neglect <ul style="list-style-type: none"> <li>○ Bruises</li> <li>○ Lack of eye contact</li> <li>○ Response to physical touch</li> <li>○ If you notice any of these during personal care, report them to the charge nurse immediately as each may be a sign of abuse</li> </ul> </li> </ul>
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Summing Up:

- Resistance to personal care is usually based on the disease process—the person with Alzheimer’s disease may not be able to understand what’s happening, leading to feelings of fear or embarrassment
- Your approach sets the tone for how personal care will be received. Your feelings will be mirrored
- Be sure to break down tasks and build on remaining abilities
- Allow for time when doing personal care so that the person with Alzheimer’s disease may participate

## **Families (45 minutes)**

### **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**

### **Introduction:**

Families have been coping with the effects of dementia long before they seek outside help. Some families may have worked through their feelings while others have kept it bottled up. Families are part of the care team and their assistance and knowledge is vital for quality care.

### **The topics of this section are**

- Empathizing 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
- 
- Understand the unique opportunity for a long term relationship with the resident and family
    - Disease process is lengthy
      - Can last up to 20 years



- Sensitivity to families throughout the process
  - Families go through many emotions throughout the disease process
  - May not know how to cope with progression
    - May not know what to expect
      - Know resources to help them
      - Find ways to educate and alert them to changes
        - Calling families in advance
        - Letting them know as soon as they arrive at the facility what to expect
  - Role modeling
    - Families don't always know how to interact
  - Grief and loss while a loved one is still living
    - Guilt often accompanies
- Empathize with feelings that persons with AD and their families experience
  - Potential feelings a family member may be coping with
    - **Denial**—this helps keep our distance from horrible news, it protects us and helps us control how much information we let in and when

- |  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
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|  | <ul style="list-style-type: none"><li>• <b>Frustration</b>—They 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</li><li>• <b>Isolation</b>—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</li><li>• <b>Guilt</b>—Family members may feel like they are not doing enough to help their loved one, they may be breaking promises they made to their loved one, or be ashamed to ask for outside help</li><li>• <b>Anger</b>—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 one by commanding and demanding</li><li>• <b>Loss/grief</b>—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</li></ul> |
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	<ul style="list-style-type: none"><li>• <b>Letting go</b>—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 hours of the day. Sometimes this leads to feelings of relief which can be almost difficult to cope with</li> <li>○ Identify strategies for helping families cope<ul style="list-style-type: none"><li>• Know what families are looking for from care providers:<ul style="list-style-type: none"><li>• <b>Kindness and respect</b>—families want to know their loved one is being treated this way as well</li> <li>• <b>Looks are important</b>—What is important to one family may not be important to another. If the resident looks clean, cared for, and happy, the family will be more pleased with the staff</li> <li>• <b>Extras</b>—Putting on a little lipstick or even a tie may make the family feel even better about the care their loved one is receiving</li> <li>• <b>Staff that show they care</b></li></ul></li></ul></li></ul>
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<p style="text-align: center;">✓ F-Tags</p> <p><b>F226:</b> Staff treatment of residents <b>F243/244:</b> Participation in resident and family groups <b>F280:</b> Care plans</p>	<ul style="list-style-type: none"> <li>○ Identify appropriate conflict resolution skills <ul style="list-style-type: none"> <li>● Overcoming denial <ul style="list-style-type: none"> <li>● Remember that denial can be healthy if it doesn't go on too long</li> <li>● Educate in small doses, have brochures and written materials available</li> <li>● Do not push too hard, give them time to adjust</li> <li>● Encourage support group attendance</li> <li>● Difficulty accepting change <ul style="list-style-type: none"> <li>○ Acknowledge their skepticism up front</li> <li>○ Ask them to listen carefully to a suggestion</li> <li>○ Ask them what they think might work</li> <li>○ Ask another family member to be a mentor</li> </ul> </li> </ul> </li> </ul> </li> <li>● Lack of understanding about Alzheimer's disease <ul style="list-style-type: none"> <li>● Direct them to an educational program</li> <li>● Go through printed materials with them</li> <li>● Use the internet and e-mail appropriately</li> <li>● Unrealistic expectations <ul style="list-style-type: none"> <li>○ Invite them to care plan meetings</li> <li>○ Let them know the consequences of expecting too much from their loved one</li> </ul> </li> <li>○ Describe staff goals and</li> </ul> </li> </ul>
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	<p>expectations</p> <ul style="list-style-type: none"> <li>• Critical-Angry-Never Happy <ul style="list-style-type: none"> <li>○ Be sure you are listening to legitimate concerns</li> <li>○ Ask them to write out a list of what's wrong and what's working well</li> <li>○ Appoint one spokesperson from the staff or ask a third party to mediate</li> <li>○ Make sure your care philosophy and plan is clear to family members</li> <li>○ Give them feedback on how their criticism is received by staff</li> </ul> </li> </ul> <ul style="list-style-type: none"> <li>• Identify and inform families of internal and external resources <ul style="list-style-type: none"> <li>○ Identify what staff handle key areas <ul style="list-style-type: none"> <li>• Know for yourself who handles each area of the facility functions, from housekeeping to dietary to administrative issues</li> <li>• Know who you should direct family members to for concerns about care issues</li> </ul> </li> <li>○ Alzheimer's Association <ul style="list-style-type: none"> <li>• All services for families are free of charge <ul style="list-style-type: none"> <li>• Helpline—1-800-372-3900 <ul style="list-style-type: none"> <li>○ Information and referral services</li> <li>○ Empathetic listening and support</li> </ul> </li> </ul> </li> </ul> </li> </ul> </li> </ul>
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	<ul style="list-style-type: none"><li>○ Lists of agencies and supports</li><li>○ Ideas and information on caregiving</li><li>○ Access all other services</li><li>○ Available 24 hours a day, 7 days a week</li> <li>● Family Education<ul style="list-style-type: none"><li>○ Basic overview program featuring a medical professional and a lawyer</li><li>○ Specialized programs on topics such as nursing home expectations, communication strategies, coping with grief and loss, etc.</li></ul></li> <li>● Support Groups<ul style="list-style-type: none"><li>○ Support groups throughout the state</li><li>○ Helps families learn from each other</li></ul></li> <li>● Care Consultation<ul style="list-style-type: none"><li>○ Gives one-on-one attention and follow up</li></ul></li> <li>● Safe Return<ul style="list-style-type: none"><li>○ National program that assists in the return of someone who has wandered</li></ul></li></ul>
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	<ul style="list-style-type: none"> <li>○ Area on Agency on Aging <ul style="list-style-type: none"> <li>● Pre-admission screening</li> <li>● Information and referral</li> </ul> </li> <li>● Identify strategies for building a positive relationship with the family <ul style="list-style-type: none"> <li>○ Show support for families <ul style="list-style-type: none"> <li>● <b>Family tours</b>—Be sure staff responsibilities and how difficult situations are handled are included</li> <li>● <b>Communicate</b>—Participate in active listening. “What I hear you say is ...” Never assume you know what the problem is.</li> <li>● <b>The transition period</b>—Encourage calls and visits. Once a family feels comfortable and that their concerns have been addressed, the calls will decrease</li> <li>● Support a grieving or frustrated family member’s feelings by validating their emotions</li> <li>● Help the family develop realistic expectations</li> <li>● Help the family understand what’s normal for someone with dementia</li> <li>● Compliment the family on their role as caregivers</li> <li>● Report good news often</li> </ul> </li> </ul> </li> </ul>
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- Families want to know about difficulties—try to be sensitive in communication and ask for their ideas or tell how you’ve solved it

- Promote successful visits

- It can be difficult for families to know what to do or how to behave when the visit. Offer suggestions and support
  - Bring in family videos or pictures
  - Play simple card games, not worrying about rules
  - Visit during scheduled activities
  - Bring lotions and give a hand massage
  - Read from a favorite book

Summing up:

- Families have a lot of emotions that need to be validated. We need to empathize and help them direct their concerns
- Families may need ideas on where to go to get further assistance, both in the facility and in the community. It’s important that we know where to direct them
- Building positive relationships allows families to maintain a relationship with their loved on and help the professional caregivers.



## Closing Statements/Review

- Dementia is the umbrella term for a group of symptoms; specifically, a progressive decline in cognitive function severe enough to affect everyday life. Alzheimer's disease is the most common form of dementia.
- Stages are used as a point of reference only. A person does not automatically move from stage to stage overnight. We need to have realistic expectations of what a person can and can't do because of the disease process.
- Person centered care is a care philosophy that puts the person first, promoting good health, positive relationships, and tending to a persons entire well-being.
- Strategies such as understanding a person's social history, developing a relationship, and taking care of your own needs will help us achieve person centered care.
- Taking care of yourself is just as important as taking care of your residents.
- Good communication is vital to providing quality care. We must use verbal and nonverbal communication strategies in order to communicate and listen well.
- Validation, or acknowledging another's feelings, is vital. Remember that behaviors are a form of communication and to look for their meaning.
  
- Behaviors are a form of communication. Each

	<p>behavior needs to be carefully examined for the message it may be sending. We need to not judge or label people based on their behaviors. Instead of looking at each behavior as a problem, we need to find the characteristic about the behavior that is a strength.</p> <ul style="list-style-type: none"><li>▪ Your approach sets the tone for how personal care will be received. Your feelings will be mirrored.</li><li>• Families have a lot of emotions that need to be validated. We need to empathize and help them direct their concerns.</li><li>• Families may need ideas on where to go to get further assistance, both in the facility and in the community. It's important that we know where to direct them. Building positive relationships with families allows them to maintain a relationship with their loved one and helps the professional caregivers.</li></ul>
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# notes

**Tab**

**Module 4:  
Regulatory Standards and Reducing Deficient Practices**

**Objectives:**

- Overview of F-Tags and regulations related to the care of dementia residents
- Investigate key safety concerns and potential solutions
- Understand resident rights and dignity and their relationship to person centered care
- Explore family needs and potential opportunities
- Understand potential situations leading to abuse and neglect, including prevention and intervention strategies
- Determine possible quality indicators

## Commonly Cited F-Tags

**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.

Current Status	Improved Implementation	Actions Steps	Deadlines

**157: Notification of changes.**

A facility must immediately inform the resident; consult with the resident’s physician; and if known, notify the resident’s legal representative or an interested family member when there is—

(B) A change in resident rights under Federal or State law or regulations as specified in paragraph (b)(1) of this section

Current Status	Improved Implementation	Actions Steps	Deadlines

**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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**207: Equal access to quality care.**

- (1) A facility must establish and maintain identical policies and practices regarding policies and practices regarding transfer, discharge, and the provision of services under the State plan for all individuals regardless of source of payment;
- (2) The facility may charge any amount for services furnished to non-Medicaid residents consistent with the notice requirement in 483.10(b)(5)(i) and (b)(6) describing the charges; and
- (3) The State is not required to offer additional services on behalf of a resident other than services provided under the State plan.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**221/222: Resident behavior and facility practices.**

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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**223: Abuse.**

The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>



**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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**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.

Current Status	Improved Implementation	Actions Steps	Deadlines

**242: Self-determination and participation.**

The resident has a right to

- (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

Current Status	Improved Implementation	Actions Steps	Deadlines

**243-244: Participation in resident and family groups.**

(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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**245: Participation in other activities.**

A resident has the right to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**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.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**280: Care plans.**

A comprehensive care plan must be—

- (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 reviewed and revised by a team of qualified persons after each assessment.

281-282: Professional standards of quality.

The services provided or arranged by the facility must

- (iii) Meet professional standards of quality and;

Be provided by qualified persons in accordance with each residents written plan of care

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**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.

Current Status	Improved Implementation	Actions Steps	Deadlines

**310: Activities of daily living.**

**Based on the comprehensive assessment of a resident, the facility must ensure that**

(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—

- Bathe, dress, and groom;
- Transfer and ambulate;
- Toilet;
- Eat; and
- Use speech, language, or other functional communication systems.

Current Status	Improved Implementation	Actions Steps	Deadlines

**323-324: Accidents**

The facility must ensure that

- (3) The resident environment remains as free of accident hazards as is possible;
- (4) Each resident receives adequate supervision and assistance devices to prevent accidents.

Current Status	Improved Implementation	Actions Steps	Deadlines

**353: Nursing services.**

The facility must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care.

Current Status	Improved Implementation	Actions Steps	Deadlines

**495: Competency.**

A facility must not use any individual who has worked less than 4 months as a nurse aide in that facility unless the individual—

- (iv) Is a full-time employee in a State-approved training and competency evaluation program;
- (v) Has demonstrated competence through satisfactory participation in a State-approved nurse aide training and competency evaluation program or competency evaluation program; or
- (vi) Has been deemed or determined competent as provided in 483.150 (a) and (b).

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**497: Regular in-service education.**

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—

- (iv) Be sufficient to ensure the continuing competence of nurse aides, but, must be no less than 12 hours per year;
- (v) 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 for nurse aides providing services to individuals with cognitive impairments, also address the care of cognitively impaired.

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>

**498: Proficiency of nurse aids.**

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

<b>Current Status</b>	<b>Improved Implementation</b>	<b>Actions Steps</b>	<b>Deadlines</b>





### F-Tags

f323/324:  
accidents

f221/222:  
resident behavior and facility  
practices

f157:  
notification of changes

## Safety Concerns

### Environmental implications of physiological changes

- **Vision**—Use brighter lights, blues and greens difficult to see, watch for glares
- **Hearing**—Use sound absorbing materials, minimize unnecessary noises
- **Thermal regulation**—Keep temperatures warm
- **Tactile sensation**—Avoid small handles, latches, and key rings
- **Musculoskeletal**—Chairs should have arms that extent to the front edge of the seat and no cross bar between front legs
- **Balance**—Use night lights, provide things to hold on to
- **Gait**—Avoid uneven flooring surfaces or changes in levels between different materials

### Security

- People with dementia may not be able to judge unsafe situations or potential hazards. The goal is to provide a protective environment that still encourages autonomy.

## 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

**f157:**  
**notification of changes**

**f163:**  
**be fully informed**

**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**

## **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

**Indiana State Department Of Health**  
**Policy and Procedures on Abuse and Neglect**

TITLE: REPORTABLE UNUSUAL OCCURRENCES

PURPOSE: To insure that reportable occurrences are recorded and monitored to facilitate compliance with state and federal laws.

POLICY: All unusual occurrences reported to the Indiana State Department of Health will be recorded and tracked or monitored to insure residents are receiving appropriate care and services.

PROCEDURE: Facilities are required by law to report unusual occurrences within 24 hours of occurrence to the Long Term Care Division. CFR 483.13(c)(2) states that "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)."

The following are examples of occurrences that the Long Term Care Division considers reportable under both State Rule and Federal Regulation. These occurrences will be recorded by facility and will be tracked and monitored.

(1) ABUSE - Physical, Sexual, Verbal and/or Mental (known and/or alleged)

Abuse is **willful** infliction of injury, unreasonable confinement, intimidation or punishment with resulting physical harm or pain, anguish, or deprivation by an individual of goods or services that are necessary to attain or maintain physical, mental, or psychosocial well being.

(A) PHYSICAL ABUSE

- 1) Resident to resident abuse that results in physical injury;
- 2) Staff to resident abuse with or without injury;
- 3) Other (visitor, relative) to resident abuse with injury.

(B) SEXUAL ABUSE

- 1) Staff to resident;
- 2) Resident to resident non-consensual sexual acts;
- 3) Resident to resident - sexual acts when both parties are considered mentally incompetent or dependent, and injury is sustained;

- 4) Other (visitor, relative) to resident non-consensual sexual acts.

(C) VERBAL ABUSE - Episodes of oral, written, and/or gestured language that includes disparaging and derogatory remarks to residents.

- 1) Staff to resident - a single traumatic episode;
- 2) Resident to resident verbal threats that cause distress to the resident.

(D) MENTAL ABUSE - Episodes of behavior toward a resident which include but are not limited to humiliation, harassment, threats of punishment or deprivation.

- Staff to resident - a single traumatic episode;

(2) UNUSUAL DEATH

Death of a resident that is unusual and/or the result of an accident.

(3) SIGNIFICANT INJURIES

A) Examples, but not inclusive of all:

- 1) injuries sustained while a resident is physically restrained;
- 2) large areas of contusions or large lacerations as defined in facility policy;
- 3) fractures sustained by a totally dependent (as defined on MDS) resident;
- 4) burns greater than first degree;
- 5) serious unusual and or life threatening injury;
- 6) Choking resulting in hospitalization.

B) Medication errors that caused resident harm or require extensive monitoring for 24-48 hours.

(4) RESIDENT ELOPEMENT

- A) A cognitively impaired resident who was found outside the facility and whose whereabouts had been unknown;
- B) Any circumstance of elopement which required police notification.

(5) EPIDEMIC OUTBREAK, QUARANTINE, AND/OR BIO-TERRORISM ACTS

Disease incident rate that is greater than the expected baseline, based on facility infection control policy.

(6) POISONINGS

(7) UTILITY INTERRUPTION

A) An interruption which interferes with the health and safety of residents in one or more major utility to the facility, such as electrical, water supply, plumbing, i.e., sewage disposal/backup, heat or air conditioning, fire alarm, sprinkler system or phone services.

B) Any interruption of utility services due to non-payment.

(8) STRUCTURAL DAMAGE

Structural damage to building due to natural disasters such as tornadoes, flooding, earthquakes, or catastrophes.

(9) ABANDONMENT

Employee(s) that walks off the job leaving residents unattended which results in the facility being unable to adequately care for the residents needs and the resident(s) are in jeopardy.

(10) MISAPPROPRIATION OF RESIDENTS FUNDS OR PROPERTY

Misappropriation of resident property is defined as the patterned or deliberate misplacement, exploitation, or wrongful, temporary or permanent use of a resident's belongings or money without the resident's consent.

(11) WIDESPREAD RODENT AND/OR INSECT INFESTATIONS

(12) FIRES – within facility due to any cause.

**FACILITY REPORTING AND INVESTIGATION INSTRUCTIONS:**

Facility must contact the ISDH by telephone (317/233-7442), voice mail (317/233-5359), or fax (317/233-7494) within 24 hours upon determining a situation exists (or existed) that is reportable under these guidelines. The after hours telephone number is 317/233-8115.

The initial report should contain a brief description of the occurrence, brief description of investigative action initiated and a description of the action taken by the facility to respond to the situation.

The results of all investigations must be reported to ISDH in writing or by fax within five (5) working days of the occurrence. The follow-up report should include the following:

- 1) Nature of occurrence, including time and place of occurrence;
- 2) Investigative action;
- 3) Other persons or agencies to whom occurrence was reported e.g. Adult Protective Services, etc.;
- 4) Plan of action/interventions implemented to prevent similar occurrences;
- 5) Method in which facility will continue to monitor efficacy of interventions.

If the above five (5) points have already been included in the initial report, a five (5) day follow-up report is not necessary (this must be indicated on the submitted initial/follow-up report).

Each occurrence will be entered into the ISDH Long Term Care database. Cumulative data of occurrences will be provided to the surveyor at the time of each facility survey.

ISDH may call for further information to determine if the occurrence is to be investigated by a surveyor. Occurrences may be investigated as a complaint based on scope and severity or evidence of a pattern.

Signature on file 11/30/2001

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Division Director

Date





**BRIEF DESCRIPTION OF INCIDENT (CONT)**

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**2.**

**TYPE OF INJURY/INJURIES**

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**3.**

**IMMEDIATE ACTION TAKEN**

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**4.**

**PREVENTIVE MEASURES TAKEN**

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---

---

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  
 – *bv debbie estrav*

## 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

They 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.

### Isolation

As the disease progresses, family and friends may have begun to pull away from the primary caregiver,

**how have you helped families?**

**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**

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 hours of the 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 to long
- Educate in small doses, have brochures and written materials available
- Do not push to 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

Resource guides for regional areas are available by calling the Alzheimer's Association at (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 would you add to this list?**

**possible quality indicators  
specific to your facility:**

## **Quality Indicators**

- Number and frequency of medication adverse effects
- Proportion of residents who are over-sedated
- Incidence of falls, fractures, and elopements
- Prevalence of restraints
- Incidence and prevalence of skin breakdown
- Incidence of symptomatic urinary tract infections
- Incidence of dehydration
- Use of futile or undesired treatments
- Moment by moment comfort of residents
- Comfort of caregiving staff
- Ability of staff to deal confidently with situations
- A coherence between values expressed in mission and actual practice
- Prevalence of agitated behaviors
- Prevalence of fecal impaction
- Prevalence of weight loss
- Incidence of decline in ROM
- Prevalence of little or no activity

# 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