



CARING FOR THE PERSON
WITH ALZHEIMER'S AND
OTHER DEMENTIA DISEASES
(3-HOUR SELF-LEARNING MODULE)

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PURPOSE

The purpose of this self-learning module is to provide the healthcare professional with the knowledge, skills and attitudes to care for and assist patients and caregivers affected by Alzheimer's disease and related disorders.

OBJECTIVES

Following completion of this self-learning module, the learner will be able to:

1. discuss the process for diagnosis of Alzheimer's disease and other dementia disorders.
2. recall behavioral symptoms of Alzheimer's disease and other dementia disorders.
3. describe three decisions that patients and caregivers affected by Alzheimer's disease and other dementia disorders may need to make during the course of the disease.
4. describe two physical and emotional symptoms associated with Alzheimer's disease and interventions to help manage those symptoms.
5. discuss two interventions the healthcare professional can use to assist the patient/caregiver in the decision-making process or when ethical conflicts arise.
6. describe the physical, emotional and spiritual impact of Alzheimer's disease and other dementia disorders on family members and implement interventions to assist them with these issues.
7. discuss effective techniques to manage behavioral symptoms and help communicate effectively with the Alzheimer's patient.
8. discuss alternatives to physical restraints.
9. discuss ethical principles related to caring for patients with Alzheimer's disease and other dementia disorders.
10. recall 3 signs of elder abuse and next steps
11. list five community resources that may be helpful to patients and their families/caregivers who are living with AD and other dementia disorders.

***Read the content and complete the learning activities in the module.
When you have completed this self-learning module, take the post-test.
Check your answers with the module answer sheet. If you have at least
70% right (14 correct answers), you have successfully completed this
module.***

INTRODUCTION

Dementia is the progressive loss of intellectual functioning severe enough to interfere with activities of daily living. Dementia is not a specific disease but is a symptom of other disorders of which Alzheimer's disease is one type.

Having dementia does not always mean that a person has Alzheimer's disease, but having Alzheimer's disease does mean that the person will experience dementia.

Alzheimer's disease is the leading cause of dementia. The hallmark symptom of Alzheimer's disease is progressive dementia. In order to understand what dementia is, it may be helpful to examine what dementia is not. Dementia is not amnesia, in which there is an inability to remember but in which other cognitive functions are intact.

Memory can be impaired by head injury or affected by the influence of drugs or alcohol. And as discussed previously (in Alzheimer's disease and other Dementia Disorders, Part I) dementia is not delirium, which is a disorder of perception and the inability to keep attention on any given task. Delirium is due to some physical cause such as electrolyte imbalance from dehydration, presence of an infection, hepatic encephalopathy or many other medical conditions. The underlying cause of delirium can be treated, and the condition resolved. Dementia is not the mild cognitive impairment associated with benign forgetfulness of age or stress when the use of lists, notes and memory prompts can help compensate for memory loss.

Dementia is an illness characterized by memory impairment and at least one additional cognitive deficit. These deficits must be severe enough to cause problems in occupational or social functioning and must represent a decline in function from the patient's previous intellectual function and abilities. Other deficits may include:

- Aphasia: the loss of ability to communicate or understand, either by speech, writing or signs
- Apraxia: the loss of ability to perform purposeful movements or to use objects correctly such as tying shoes or remembering how to use a fork
- Agnosia: the loss of the ability to understand or interpret sensory input including
- Auditory: the mental inability to interpret sounds
- Tactile: inability to distinguish objects by sense of touch
- Optic: inability to correctly interpret images seen, may include hallucinations
- Disturbance in executive function: the loss of ability to plan and think ahead, especially tasks that require multiple steps or sequencing
- Delusions and suspiciousness: the fear that someone is "out to get them" or accusing other of stealing their belongings. Behaviors include hiding things (and forgetting where they are hidden) so that other people don't "steal" them and "sundowning" (increased confusion and agitation in the evening)
- Repetitive actions or questioning such as fidgeting, shredding paper or tissue, twisting clothing or calling out a name or phrase repeatedly
- Loss of social graces (disinhibition): Loss of social graces leads person to do what feels good to them at the moment including inappropriate sexual behavior, without concern about social norms and expectations. A previously quiet and polite person may seem rude and abrupt and say what they think or feel without regard to how their behavior may seem or feel to others.

DIAGNOSING A DEMENTIA DISEASE

Patients experiencing symptoms of cognitive impairment should be thoroughly evaluated by a physician and other healthcare professionals in order to determine a diagnosis. Diagnosis of Alzheimer's disease or other dementia diseases is made through medical and family history, physical, neurological and mental status examinations, laboratory tests and brain scans. Once diagnosis is made, cognitive assessments are done to determine a baseline of cognitive function, the level of cognitive impairment and staging of the disease (mild, moderate, and severe).

Remember that the only way to definitively determine the presence of Alzheimer's disease and a few of the other dementia-related diseases is through a post-mortem biopsy. Alzheimer's disease, however, has a characteristic pattern of symptoms and can be diagnosed reliably by history and physical examination performed by an experienced physician. The following diagnostic evaluations may be used to gather information in making a diagnosis of the cause of presenting dementia symptoms.

Health history to determine

- dementia symptoms experienced, when they began and if they have worsened
- information about current and past illnesses
- medications the patient is currently or has recently been taking
- assessing nutritional status
- current or history of alcohol and/or illegal drug use
- history of familial medical conditions, especially family history of Alzheimer's disease or other dementias

Physical examination including:

- blood tests to assess for metabolic imbalances, evidence of cardiovascular disease, anemia or malnutrition, diabetes or other major organ disease
- neurological exam to test reflexes, coordination and balance, muscle tone and strength, speech, eye movement

Brain imaging (or scans) which can provide information about the structure and function of the brain including:

- Magnetic resonance imaging (MRI) and computerized tomography (CT) scan to provide structural information about the shape, position or volume of brain tissue. These tests can be used to detect tumors or damage from strokes or head trauma which could be causing symptoms of dementia.
- Positron emission tomography (PET) and functional MRI (fMRI) scan can show how well cells in different areas of the brain are working by showing how actively the cells use sugar or oxygen.

Mental status assessment (tests of memory, problem solving, attention, math and language skills)

- Mini-mental state exam (MMSE) which asks the person a series of questions designed to test a range of everyday mental skills. Examples of these questions include asking the person to state the year, season, day of week and date, to count backward by 7s or spell the word "world" backwards.

- Mini-cog which involves (1) asking the person to remember 3 common objects and repeat them back a few minutes later (2) drawing a clock face and correctly positioning the hands of the clock to a time specified by the examiner
- Presence of mood disturbances, such as depression, anxiety, and other mood disorders than can cause problems in memory and other symptoms that overlap with dementia.

HEALTH HISTORY

A history of symptoms should be collected from the patient and the family in terms of type, onset and progression. In addition, collecting a history of other illnesses or issues such as depression, drug reactions, alcohol or drug use, recent losses and other events that could cause memory loss is important in ruling out other causes of dementia.

Collecting a family history, including the presence of dementia-related disorders is important in determining a diagnosis. There are many dementia-related illnesses, some of which may have a genetic cause. Genetics play a role in some persons with Alzheimer's disease.

A PHYSICAL AND NEUROLOGICAL EXAMINATION

A physical and neurological examination is made to assess the patient's overall appearance and determine his/her functional abilities including gait, ambulation, and ability to perform ADLs (activities of daily living). These exams also help rule out other physical diseases that could cause dementia.

Laboratory tests can help determine the presence of vitamin deficiencies, neurosyphilis, diabetes, pernicious anemia, electrolyte imbalances, or infections that could cause memory loss and/or cognitive decline. An EEG (electroencephalograph) and an ECG (electrocardiogram) may be able to show the presence of a seizure disorder or other organic brain disease.

BRAIN SCANS

Currently, the PET scan and MRI scan is used primarily in research studies in hopes of gaining knowledge in diagnosing Alzheimer's disease and monitoring progression. Medicare will cover the PET scan only to help differentiate (distinguish) the disease from frontotemporal dementia (a rare related disorder). Another promising area of brain imaging research is working to develop tracer compounds that can be used to tag abnormal brain deposits. In late stages, the MRI may show a decrease in the size of certain areas of the brain. While the scans cannot confirm the diagnosis of Alzheimer's disease, they can exclude other causes of dementia (such as stroke or tumor).

MENTAL STATUS ASSESSMENT

An assessment of the patient's mental status is essential in providing an accurate diagnosis. In addition to diagnosis, assessment of the patient's cognitive function should be ongoing in order to help healthcare professionals:

- determine the stage of the disease to plan care and appropriate treatment
- anticipate the patient and family's needs
- address decision making issues and complete advance directives so patient choices are honored

- educate about possible changes in the patient's condition
- determine needed resources
- document to decline and symptoms of disease progression

While there are numerous scales and systems available to assess and classify the stages of Alzheimer's disease and other dementia diseases, it is important to understand that there are seldom clear lines between the stages. The various stages of dementia may overlap, and a patient may move back and forth between stages before they decline further.

RISK FACTORS AND STAGES OF ALZHEIMER'S – ADVANCES IN RESEARCH

Doctors may soon have new tools and tests to help diagnosis Alzheimer's earlier. It is believed that changes in the brain occur many years before symptoms are evident. Researchers are developing different tests, called biomarkers, which may help diagnose Alzheimer's earlier. MRI and PET imaging also help monitor changes in the brain.

Biomarkers help identify disease risk. They are used for early identification, diagnostic or monitoring purposes. For example, blood glucose is a biomarker for diabetes risk, as well as a way to monitor treatment effectiveness.

Biomarkers for Alzheimer's include measuring levels of specific proteins such as beta-amyloid and tau found in the blood and cerebral spinal fluid.

The benefit in identifying Alzheimer's disease earlier is to be able to offer medications and treatments at an earlier stage when they may be more effective in maintaining and preserving brain function. Biomarkers will continue to play an important role in disease diagnosis and management as new drugs and treatments to treat Alzheimer's are developed.

This research has sparked the National Institute of Aging and the Alzheimer's Association to propose new criteria and guidelines for diagnosis. Research and testing are continuing, so these guidelines are not yet ready for use in clinical settings. The recommendations proposed include three stages in the Alzheimer's disease continuum.

These guidelines will provide another way to look at the question of staging. These three stages show a long disease continuum that spans many years. The more commonly used seven stages of dementia developed by Barry Reisburg which will follow.

Early, preclinical: no symptoms.

Researchers believe that changes occur in the brain up to 20 years before clinical symptoms are noticed. Cerebral spinal fluid and blood tests can detect the presence of certain proteins such as beta-amyloid and tau, but more research must still be done to see if this is an effective way to diagnosis Alzheimer's at such an early stage.

Middle Stage: mild cognitive impairment.

At this point the person shows mild cognitive impairment. Symptoms such as forgetfulness and changes in a person's thinking ability are more noticeable, but the person remains able to function in an independent manner. When mild cognitive impairment includes memory problems, the person is more likely to develop dementia, but not always. At this point, biomarker testing may help identify those who have a higher risk of developing Alzheimer's.

Final stage: Alzheimer's dementia

This is the symptomatic stage that encompasses memory, thinking and behavior. The person needs supervision and functional ability is impaired. The person may have difficulties other than memory loss, such as trouble finding words, impaired reasoning and vision/spatial deficits. Dementia symptoms and stage progression varies with each individual and presents uniquely. The Global Deterioration Scale, the Mini-mental State Examination, and the Functional Assessment Staging Scale are examples of scales used to assess the relative level and stage of dementia impairment.

GLOBAL DETERIORATION SCALE

Global Deterioration Scale (GDS)

The Global Deterioration Scale (GDS) was developed in 1982 and used to assess cognitive function. This scale may also be helpful as an education tool to use with caregivers. It can help caregivers identify symptoms that are reliable indicators of dementia disease and where in the course of probable progression the patient is functioning. Identifying clinical characteristics may help caregivers remember that difficult behaviors are often the result of a disease process over which the patient has no control and that accommodations for continued decline should be planned.

Stage 1: No Cognitive Impairment

Unimpaired individuals experience no memory problems, and none are evident to a health care professional during a medical interview.

Stage 2: Very Mild Cognitive Decline

Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

Stage 3 Mild: Cognitive Decline

Friends, family, or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- word- or name-finding problems noticeable to family or close associates
- decreased ability to remember names when introduced to new people
- performance issues in social or work settings noticeable to family, friends or co-workers
- reading a passage and retaining little material
- losing or misplacing a valuable object
- decline in ability to plan or organize

Stage 4: Moderate Cognitive Decline

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- decreased knowledge of recent occasions or current events
- impaired ability to perform challenging mental arithmetic—for example, to count backward from 100 by 7s
- decreased capacity to perform complex tasks, such as marketing, planning dinner for guests or paying bills and managing finances
- reduced memory of personal history
- the affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

Stage 5: Moderately Severe Cognitive Decline

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated.
- become confused about where they are or about the date, day of the week, or season.
- have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s.
- need help choosing proper clothing for the season or the occasion.
- usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children.
- usually require no assistance with eating or using the toilet.

Stage 6: Severe Cognitive Decline

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:

- lose most awareness of recent experiences and events as well as of their surroundings.
- recollect their personal history imperfectly, although they generally recall their own name.
- occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces.
- need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet.
- experience disruption of their normal sleep/waking cycle.
- need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly).
- have increasing episodes of urinary or fecal incontinence.
- experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as handwringing or tissue shredding.
- tend to wander and become lost.

Stage 7: Very Severe Cognitive Decline

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.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered.
- Individuals need help with eating and toileting and there is general incontinence of urine.
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.
-

FUNCTIONAL ASSESSMENT STAGING SCALE (FAST)

The Functional Assessment Staging Scale (FAST) is a screening test to quantitatively assess the degree of disability, to stage the disease and to document changes that occur over time. It is not intended to serve as the sole criterion for diagnosing dementia or to differentiate between various forms of dementia. According to the National Hospice Organization's Medical Guidelines, patients classified as Stage Seven of the FAST are those who are considered terminal and appropriate for hospice care. It should be noted, however, that admission to hospice should not depend solely on the results of one assessment scale. The (FAST) has score which have been correlated with scores on the Mini Mental State examination (MMSE).

The FAST assessment tool is completed through interview with the patient and caregivers as well as through observation by the healthcare professional. The FAST score is the highest consecutive level of disability based on the following guidelines.

Functional Assessment Scale (FAST) – the FAST scale has 7 stages:

- 1 Normal Adult
 - a) No difficulty either subjectively or objectively.
- 2 Normal Older Adult
 - a) Complains of forgetting location of objects.
 - b) Subject work difficulties.
- 3 Early Dementia
 - a) Decreased job functioning evident to co-workers.
 - b) Difficulty in traveling to new locations.
 - c) Decreased organizational capacity. *
- 4 Mild Dementia
 - a) Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.
- 5 Moderate Dementia
 - a) Requires assistance in choosing proper clothing to wear for the day, season or occasion, e.g., patient may wear the same clothing repeatedly, unless supervised. *
- 6 Moderately Severe Dementia
 - a) Improperly putting on clothing without assistance or cueing (e.g., may put street clothes on overnight clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.

- b) Unable to bathe properly (e.g., difficulty adjusting bath-water temperature) occasionally or more frequently over the last weeks.
 - c) Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.
 - d) Urinary incontinence (occasionally or more frequently over the past weeks.) *
 - e) Fecal incontinence (occasionally or more frequently over the past weeks.) *
- 7 Severe Dementia
- a) Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.
 - b) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intense interview (the person may repeat the word over and over).
 - c) Ambulatory ability is lost (cannot walk without personal assistance).
 - d) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair).
 - e) Loss of ability to smile.
 - f) Loss of ability to hold head up independently.

*Scored primarily on the basis of information obtained from knowledgeable informant and/or category.
Source: Reisburg, B. Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 1988; 24:653-659.

LEARNING ACTIVITY

Read the following case study and determine the patient's level of cognitive function based on the Global Deterioration Scale and determine the patient's FAST score.

Mrs. Smith is 62 years old. She was diagnosed with familial Alzheimer's disease four years ago. She recently left her job and went on disability because her co-workers had observed changes in her performance and behavior at work. They noticed that she was having difficulty with organizational skills, was having difficulty managing complex tasks like writing curriculum and putting together schedules for educational programs, and was frequently losing objects such as her briefcase, laptop computer and office supplies. She would also get lost traveling to remote locations to teach a class. Her manner of dress had also changed.

On one day she wore her pajama bottoms to work, and on one occasion she wore the same outfit for three days in a row. Recently she has had trouble finding the right word to name an object. Mrs. Smith loves to read, but she can no longer recall what she has read. She avoids going into new social settings because she can no longer remember the names of people she meets and often gets lost going to social functions. She has begun to experience anxiety about going to even familiar places like the grocery store or doctor's office. She remains oriented to time and place and is still aware of current events. She can still recognize people familiar to her.

*What is Mrs. Smith's level of functioning on the Global Deterioration Scale?

*What is Mrs. Smith's FAST score?

MINI-MENTAL STATE EXAMINATION

The Mini-Mental State Examination (MMSE) is a screening test to quantitatively assess the severity of cognitive impairments and to document cognitive changes that occur over time. It is not intended to serve as the sole criterion for diagnosing dementia or to differentiate between various forms of dementia. However, MMSE scores may be used to classify the severity of cognitive impairment or to document serial change and decline in dementia patients.

The Mini-Mental State Examination (MMSE) evaluates cognitive impairment in relation to orientation, memory, attention and language. While it is one of the most accepted ways of evaluating cognitive status, it is important to remember the generational and cultural issues that might affect the accuracy of the test results. For example, someone who has had lifelong difficulty with math skills might have difficulty counting back by 7 from 100, which is one of the required tasks for evaluation. In addition, the calculator generation may also have trouble with this task as they are not comfortable or practiced in using mental math. Because the Mini-mental is a standard test, it can be used to determine a baseline of cognitive function. On the Mini-mental, scores below 27 indicate the need for further testing for cognitive function. It is thought that scores below 24 are indicative of cognitive impairment and future cognitive deterioration.

The MMSE has scores which have been correlated with scores on the Functional Assessment Staging (FAST) tool developed by Reisburg and used in determining typical time course of Alzheimer's disease. It is therefore a useful tool to support findings of the FAST scale. The MMSE is also very useful in assessing and documenting cognitive impairment in any patient which may have needs associated with mental status including age or disease-related dementia.

The MMSE consists of a variety of questions, has a maximum score of 30 points and ordinarily can be administered in 5-10 minutes.

The following three cut-off levels should be employed to classify the severity of cognitive impairment: no cognitive impairment = 24 - 30; mild cognitive impairment = 18 - 23; severe cognitive impairment = 0 - 17

The MMSE assessment tool is as follows:

Mini-Mental State Examination

Patient Score	Maximum Score	
	5 5	Orientation What is the (year) (season) (date) (day) (month)? Where are we (country) (state) (county) (city) clinic)?
	3	Registration Name three objects, allowing one second to say each one. Then ask the patient to name all three objects after you have said them. Give one point for each correct answer. Repeat them until he hears all three. Count trials and record number. <i>A p p l e ... B o o k ... C o a t</i> Number of trials ____ .

	5	Attention and Calculation Begin with 100 and count backward by 7 (stop after five answers): 93, 86, 79, 72, 65. Score one point for each correct answer. If the patient will not perform this task, ask the patient to spell "WORLD" backwards (DLROW). Record the patient spelling: _____. Score one point for each correctly placed letter.
	3	Recall Ask the patient to repeat the objects above (see Registration). Give one point for each correct answer.
	2	Language: Naming: Show a pencil and a watch and ask the patient to name them.
	1	Repetition: Ask patient to repeat the following: "No ifs, ands, or buts."
	3	Three-Stage Command: Follow the three-stage command, "Take a paper in your right hand; fold it in half; and put it on the table."
	1	Reading: Read and obey the following: "Close your eyes" (show the patient the sentence)
	1	Writing: Write a sentence
	1	Copying: Copy the design of the intersecting pentagons
	30	Total Score Possible

DIAGNOSING DEMENTIA DISEASES

Accurately diagnosing the cause of dementia disease is essential in providing appropriate treatment to the patient as well as education and counseling to the family and caregivers. Dementias can be grouped into two categories: dementia that presents at onset without prominent motor signs (movement, balance and gait) which include Alzheimer's disease, frontotemporal dementia, Creutzfeldt-Jakob and other prion diseases and dementias that present with motor signs including Parkinson's disease, Lewy body disease, hydrocephalus, Huntington's disease and vascular dementia.

The clinical symptoms and progression of any dementia varies, depending on the source and type of the disease causing it. Dementia may progress rapidly or slowly over the years and is characterized by

different pathologic (structural) changes in the brain. As discussed, diagnosis of the underlying etiology of dementia requires a complete and thorough medical evaluation. Because there is no definitive diagnostic test specific to detecting Alzheimer's disease (AD), that diagnosis is made by first eliminating other causes of the symptoms and by distinguishing between Alzheimer's disease and other degenerative diseases.

Vascular Dementia (VaD)

Vascular dementia, also known as Multi-infarct dementia, is caused by problems in the blood vessels in the brain, resulting in destruction of brain tissue. Occlusion or blockage in a blood vessel can cause a stroke. The location and severity of the blockage determines the development of dementia. Not all strokes lead to the noticeable clinical symptoms. Vascular dementia may also be caused by narrowing or constriction of the blood vessels in the brain. The damage caused by multi-infarct dementia is not reversible, but identification of causes of the strokes such as hypertension (high blood pressure), elevated cholesterol and diabetes can help change the course of the disease and possibly prevent more damage to the brain.

Symptoms of VaD are similar to the symptoms evidenced in Alzheimer's disease including, confusion, short-term memory loss, wandering and getting lost in familiar places. Vascular dementia and Alzheimer's disease often appear together, and it can be difficult to make a singular diagnosis of one of the other. Diagnostic testing through CT (computerized tomography), MRI (magnetic resonance imaging) and/or PET (positron emission tomography) can show evidence of cerebral vascular disease. This can assist the patient in getting the correct treatment to minimize dementia. This person with this disorder generally declines with intermittent periods of obvious deterioration.

Death usually occurs from a major stroke, heart disease, pneumonia or other systemic infection.

Mixed Dementia

Mixed dementia is the description used when Alzheimer's disease and vascular dementia (VaD) occur together. Autopsy results have shown that up to 45 percent of people with dementia have signs of both Alzheimer's and vascular dementia. Mixed dementia is probably more common than is currently recognized. Cognitive decline follows a varied pattern. Some experts suspect mixed dementia whenever a person has both 1) evidence of cardiovascular disease and (2) dementia symptoms that progress slowly.

Stroke

A stroke occurs when the blood supply to a part of the brain is suddenly blocked by a clot or embolus (ischemic) or when a blood vessel in the brain bursts (hemorrhagic) and the cells of the brain are thereby deprived of oxygen, are damaged and die. Symptoms of a stroke include sudden numbness or weakness, especially on one side of the body; sudden confusion or trouble speaking or understanding speech; sudden trouble seeing in one or both eyes; sudden loss of balance or coordination or sudden severe headache. After a stroke, the person may have difficulty with thinking, awareness, attention, learning, judgment and memory. Stroke patients may have difficulty in understanding and communicating. Many stroke patients may have difficulty with mood, emotional expression and depression. About 25 % of people who recover from their first stroke will have another stroke within 5 years.

Dementia with Lewy Bodies (DLB)

Dementia with Lewy-Bodies can occur alone or simultaneously with Alzheimer's or Parkinson's disease. It is a neurodegenerative disorder associated with deposits of abnormal proteins (Lewy-bodies) found in the nerve cells of the affected brain. Researchers are still working to understand whether dementia with Lewy bodies is a distinct clinical entity or perhaps a variant of Alzheimer's or Parkinson's disease. Symptoms can range from traditional Parkinsonian effects, such as loss of spontaneous movement, muscle rigidity, tremor and shuffling gait, to the classic cognitive deficits associated with Alzheimer's disease.

Visual hallucinations that are well formed and detailed usually occur early in the disease process. Depression, anxiety and delusions are also more common in this type of dementia than in Alzheimer's-related dementia. In about 50% of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, when people dream they are moving, the motor center in the brain is blocked and people do not walk or run as they might be dreaming they are. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes violently and vividly. There is no treatment for this disease, and brain deterioration and severe cognitive impairment occur as the disease progresses.

Parkinson's Disease

Some patients with Alzheimer's disease show symptoms of Parkinson's disease (PD), and some patients with Parkinson's disease show signs of Alzheimer's disease. PD is a progressive, debilitating disease that affects the central nervous system, and is another disease involving Lewy bodies. Specifically, Parkinson's disease affects the brain's basal ganglia which results in decreased dopamine levels.

It is estimated that nearly 2% of those older than age 65 will develop Parkinson's disease. The disease is characterized by tremors, stiffness in joints, difficulty starting movement, shuffling gait, mask-like facial expression, speech problems, excessive salivating and sweating. In the later stages of the disease, 50 to 80% of patients with Parkinson's disease will experience dementia.

While treatment with medications such as L-dopa and antidepressants can help decrease movement problems, they cannot treat or prevent the development of dementia symptoms.

Huntington's Disease

Huntington's disease is a fatal disease that is most often characterized by involuntary movements (chorea) and cognitive decline (dementia). It is predominantly genetic and affects structure deep within the brain (basal ganglia) which are responsible for such functions as movement and coordination. As a result, the person with Huntington's may experience uncontrolled, involuntary muscle jerks and spasms, (such as twisting and turning of the limbs) and facial grimacing. Onset of the disease is usually between 30-50 years of age. Mental changes can include symptoms of depression, impaired memory and judgment, and personality changes such as irritability, moodiness and antisocial or psychotic behavior. As the disease progresses speech is slurred and clumsiness, imbalance and restlessness are common causes for falls. At end stage basic functions such as speaking, eating and swallowing are lost. There is no cure to arrest the deterioration associated with HD, but medications can help treat the uncontrollable motor movements and decrease psychiatric symptoms.

Creutzfeldt - Jakob Disease

Creutzfeldt-Jakob disease (CJD) is a fatal, rapidly progressive brain disorder caused when a misshaped prion protein begins to build up in the brain. It usually affects persons older than it is characterized by

rapidly progressive dementia. In the early stages, patients may have memory loss, behavioral changes, loss of coordination and visual disturbances. Early symptoms of cognitive decline may be associated with depression or agitation. As the illness progresses, mental deterioration is pronounced and involuntary muscle movements, blindness and coma may occur. CJD occurs rarely but is usually fatal within a year.

CJD belongs to the family of human and animal diseases known as the transmissible spongiform encephalopathies

(TSE). Spongiform refers to the characteristic appearance of infected brains, which become filled with holes which resemble a sponge under the microscope. CJD is the most common of the known human TSEs. Other TSE's are found in animals, including bovine spongiform encephalopathy (BSE) which is found in cows and is referred to as "mad cow disease." A diagnosis of Creutzfeldt-Jakob disease can only be confirmed after the death of the patient, at autopsy.

Frontotemporal Dementia (FTD) OR Pick's Disease

Frontotemporal dementia (FTD) is a rare progressive disorder that affects the temporal and frontal lobes of the brain. Abnormal "Pick's" bodies in the nerve cells of these lobes cause symptoms similar to Alzheimer's disease including loss of language abilities (aphasia), decreased ability to recognize familiar people and things (amnesia), and loss of movement (apraxia). This disease, however, differs from Alzheimer's in that early symptoms often involve marked changes in personality, judgment and social skills. Patients may make rude and offensive remarks to strangers or family. They may have symptoms resembling obsessive-compulsive disorder such as over-eating or inappropriate sexual interest. Apathy, disinterest in others and social withdrawal are early symptoms noted by caregivers. Usual onset of Pick's disease is younger than Alzheimer's disease and first appears in people in their 50s and 60s but can develop as early as 20s or as late as 80s.

Progression of FTD to death averages about 8 years. A diagnosis of Pick's disease, like many other diseases that cause dementia, can only be confirmed through autopsy.

Normal Pressure Hydrocephalus

This disease primarily affects people in their 60s and 70s and often following head injury, meningitis or neurosurgery. In normal pressure hydrocephalus (NPH), there is a build-up of intracranial fluid in the brain causing the ventricles of the brain to enlarge. As the ventricular chambers expand, they can compress and damage nearby tissue which can cause symptoms similar to those of Alzheimer's and Parkinson's disease. "Normal pressure" refers to the fact that spinal fluid pressure is often within the normal range on a spinal tap.

The three presenting symptoms that typify NPH include: (1) difficulty walking, (2) loss of bladder control, (3) cognitive decline. Cognitive impairment usually involves delayed reactions, slowed responses and general slowness in understanding. NPH can sometimes be treated by surgical insertion of a shunt to drain excess fluid from the brain, however while motor difficulties may improve, cognitive impairment is generally more resistant to treatment depending on the extent of damage to neurons prior to treatment.

SECONDARY DEMENTIA CAUSES

Dementia-like symptoms can also develop as the result of other medical conditions. If the underlying condition can be diagnosed and treated, it is possible the dementia symptom may stabilize, improve or even resolve. The following are some of the more common conditions that can lead to symptoms of dementia. Nutritional deficiencies, alcohol and substance abuse, metabolic disorders such as diabetes or kidney failure, delirium and infections can all cause dementia-like symptoms.

Nutritional Deficiencies

Electrolyte imbalances from poor nutrition or dehydration can cause confusion. Dehydration, which can usually be reversed with adequate hydration can cause symptoms of confusion and the delirium which can resemble dementia.

Vitamin deficiencies have also been linked to the onset of dementia. Wernicke-Korsakoff Syndrome, usually seen in alcoholics, is caused by a vitamin B1 (thiamine) deficiency. Problems with the absorption of B12 (pernicious anemia) can cause dementia-related symptoms including depression, irritability and personality changes. A deficiency in vitamin B6 and niacin (nicotinic acid) is linked with the development of pellagra, a neurological disorder that can be associated with delirium and eventually dementia.

Alcohol and Substance Abuse

Wernicke-Korsakoff syndrome is a disorder caused by a deficiency of thiamine (vitamin B-1). The most common known cause is alcohol abuse. Wernicke encephalopathy is the presenting acute phase, and Korsakoff psychosis is the chronic permanent phase. Patients suffer severe cognitive impairment with memory loss, weakness and loss of coordination and confabulation (the confusion of imagination with memories). Remember that patients in the early stages of other dementia-related illnesses may also confabulate or be very verbal in an attempt to hide the memory loss and forgetfulness. High dose thiamine and alcohol abstinence may reverse some of the symptoms early in the disease, but in later stages the dementia does not respond to treatment.

The long term toxic effect of illegal drugs can lead to brain damage that can cause dementia. Alcohol and drug abuse can also increase the chance of head injuries from falls and accidents, vitamin and nutritional deficiencies as well as liver and kidney damage which can cause dementia symptoms.

Metabolic Disorders

Metabolic disorders are caused when a major organ or body system fails to adequately regulate the normal biochemical functions of the body. The alteration in the body's complex chemical exchange can result in a range of symptoms. Dementia-like symptoms of confusion, memory loss, disorientation, agitation, hallucinations and other cognitive impairment can be caused by these conditions:

- Cortisol hormone disorders (such as Graves disease)
- Diabetes
- Electrolyte disorders (such as calcium and sodium imbalances)
- Kidney failure
- Liver disease
- Thyroid disease

Delirium

The word for delirium comes from the Latin term meaning “off the track,” and is not a disease but rather an array of symptoms with different causes. Delirium can be caused by infections, drug reactions, dehydration and electrolyte imbalances, fecal impaction, urinary retention, sleep deprivation and change in environment.

Delirium is often mistaken for dementia or part of old age (think of the number of patients who are elderly who become confused in the hospital). It occurs more commonly in elderly people who already have compromised mental status. Delirium is extremely common among nursing home residents. The condition is associated with increased morbidity and mortality rates.

Delirium is found in 30 to 50% of patients admitted to intensive care units and as many as 80% of patients develop delirium near death. ([medscape.com/article/288890](https://www.medscape.com/article/288890))

Main symptoms:

- Clouding of and change in level of consciousness, reduced awareness
- Difficulty maintaining attention
- Disorientation, speech disturbances
- Illusions, hallucinations
- Tremor, asterixis
- Symptoms tend to fluctuate though usually worse at night. Reversal of sleep-wake pattern is common.
- Patients with hyperactive delirium appear restless, agitated and hyper-alert

Without careful assessment delirium, which can be treated and reversed can be confused with dementia. Loss of awareness (a condition that occurs in delirium) is not a characteristic of dementia. In cases of delirium, the patient usually has an acute, sudden and simultaneous impairment of memory, thinking and perception. In patients who are elderly, delirium is often the first symptom of an underlying illness. A sudden change or increase in dementia symptoms should prompt the assessment of the person for the treatable condition of delirium.

Infections

Urinary tract infections, upper and lower respiratory tract infections and pneumonia can affect the central nervous system and cause dementia symptoms. Especially in the elderly, where dehydration also causes delirium symptoms, symptoms of confusion are often the hallmark of an infection. Prompt recognition and treatment of viral and bacterial infections may reverse dementia-like symptoms.

Other infections or viruses that affect the central nervous system:

- Meningitis is an inflammation of the membranes surrounding the brain and spinal cord. Meningitis is caused by a bacterial, viral or fungal infection and includes symptoms of fever, headache, nausea and vomiting, stiff neck and photophobia (sensitivity to light) with confusion and other changes in level of consciousness. Meningitis should be ruled out when anyone develops sudden onset of symptoms of dementia.
- Encephalitis is an inflammation of the brain itself and can be caused by viral or bacterial agents. Like meningitis, encephalitis is a serious illness that can cause dementia-like symptoms of confusion and disorientation.
- Human immunodeficiency virus (HIV) can damage neurons and cause dementia symptoms. Over 20% of HIV patients develop some symptoms of dementia. HIV clinical

trials are working to develop medications that may help to block the release of certain enzymes produced in the HIV disease process which damage healthy neurons.

Brain Injuries

A head injury can cause changes in cognition (thinking, remembering, understanding and communicating) and in emotions or behavior. These changes often improve over time, but sometimes become permanent. The most common lasting cognitive impairment among severely head-injured patients is memory loss. Many patients with mild to moderate head injuries who experience lasting cognitive deficits become easily confused or distracted and have problem with concentration and attention. Head injuries may increase the risk of dementia or cause dementia to develop at an earlier age.

The brain is a common metastasis site from cancer occurrence in the hospice patient with lung, breast or uterine cancer. Changes in cognitive function and mental status can be the result of increased intracranial pressure from tumor development in the brain.

Medication Reactions

Aging patients who take multiple medications are at risk for adverse reactions. Additionally, patients with existing cognitive impairment sometimes confuse dosing times or take multiple doses resulting in increased symptoms of cognitive impairment. Investigation of the patient's medication record, dosing schedules and any interactions is important when evaluating a patient with dementia symptoms. The following common medications can cause or exacerbate cognitive impairment and especially can increase confusion and disorientation in the elderly patient:

- Anti-convulsant medication (used for neuropathic pain)
- Antihistamines
- Sleeping medications (including OTC "PM" sleep aids)
- Tricyclic antidepressants (also used to treat neuropathic pain)
- Anti-diarrhea medication

WHAT CAUSES ALZHEIMER'S DISEASE?

Alzheimer's disease develops because of a complex series of events that take place in the brain; scientists continue to research the causes and do not yet fully understand the cause. It is likely that genetic, environmental and lifestyle factors contribute to development of the disease.

Alzheimer's disease (AD) is most commonly an age-related disease which develops after age 60. More than 90 percent of Alzheimer's disease develops in people older than 65. Although no specific gene has been identified as the cause of late-onset Alzheimer's disease, genetic factors do appear to increase a person's risk of getting the disease. In a small percentage of Alzheimer's cases (less than 1 percent) a genetic mutation can cause a change in the proper sequencing in any of 3 important genes. Inheriting the mutation in the amyloid precursor protein and in proteins called presenilin 1 and 2 guarantees that the person will develop Alzheimer's disease. In such individuals, symptoms begin to occur before age 65, and sometimes as early as age 30.

Another gene called Apolipoprotein E or APOE (ε4 gene) provides a blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits a form of this gene from each parent. In some people a person with an irregularity in the ε4 gene increases the risk of developing Alzheimer's disease. The APOE gene has several forms and one of them occurs in about 40 percent of all people who develop late-onset AD. However, at least 30% of people with Alzheimer's disease have no form of this gene.

Although Alzheimer's disease is not a normal part of aging, the risk of developing the disease rises with age. Current research from the National Institute on Aging indicates that the incidence of Alzheimer's disease doubles every 5 years over the age of 65. As our baby boomer population ages, the disease will impact a greater percentage of Americans.

Lifestyle factors, including diet, exercise, social engagement and mentally stimulating pursuits may help to reduce the risk of developing or delay the onset of cognitive decline and Alzheimer's disease. Studies continue investigating the association of cognitive decline to risk factors such as cardiovascular disease, hypertension, diabetes, obesity, alcohol and drug use and history of head injury.

During the course of the disease certain neurons (brain cells) are damaged and die. Initially affected are neurons located in the hippocampus and temporal lobe, where information which affects a person's ability to remember, speak, think and make judgments and decisions is stored. What causes these neurons to die is uncertain, but the characteristic changes in the brain can be observed after death when the brain can be examined microscopically. In particular, it is the presence of 'tangles' and 'plaques' made from protein fragments which confirm the diagnosis of Alzheimer's disease.

Hallmarks of damage in the brain associated with the disease processes of Alzheimer's disease are:

- Amyloid plaques, which are made up of fragments of a protein called beta-amyloid peptide mixed with a collection of additional proteins, remnants of neurons, and bits and pieces of other nerve cells.
- Neurofibrillary tangles (NFTs), found inside neurons, are abnormal collections of a protein called tau. Normal tau is required for healthy neurons. However, in Alzheimer's disease, tau clumps together and as a result, the nerve endings that transmit messages become tangled.
- Reduction in acetylcholine, which is an important neurotransmitter needed to relay the messages cells send to one another. This results in loss of connections between neurons responsible for memory and learning. Neurons can't survive when they lose their connections to other neurons. As neurons die throughout the brain, the affected regions begin to atrophy.

THE INTERDISCIPLINARY GROUP APPROACH TO CARING FOR PATIENTS WITH DEMENTIA

Patients with advanced Alzheimer's disease and other dementias experience many physical, emotional, and behavioral changes during the course of their disease. In the later stages of the disease, their physical and mental condition has usually deteriorated to the point where they are unable to speak intelligibly, have difficulty swallowing, have lost weight, wander aimlessly and/or experience agitation, do not respond to verbal communications, are incontinent, are unable to ambulate, and sleep for long periods of time. They may make guttural noises, moan or cry out repetitively and without obvious

reason. Due to the patient's inability to use language or communicate effectively, trying to assess and plan care to meet the patient's needs can be challenging for any one healthcare professional. Caregivers can experience fatigue and frustration trying to meet the patient's needs as well as experience an array of discomforting emotions related to changes occurring in their lives and that of the patient. Overall, patients and families affected by Alzheimer's disease and other advanced dementias are best supported through an interdisciplinary team approach to care.

The interdisciplinary group consists of the physician, social worker, nurse, chaplain, nursing assistant, volunteers, and ancillary services. The patient and family are core team members and should be involved in all aspects of planning and providing care. Each member of the team can provide his/her expertise in providing physical, emotional and spiritual care and support.

Alzheimer's disease patients and their families are unique human beings with very special care needs. Showing respect and providing dignity should be the core of all we do for patients and their families.

Key considerations in providing care to patients and families affected by Alzheimer's disease and other dementias include:

- Education
- Making Decisions
- Managing Symptoms
- Caregiver Support

PROVIDING EDUCATION

At the time of diagnosis and throughout the course of the disease, providing education to the patient, family and/or caregivers is crucial in order to meet care needs. Education should include the physical, emotional, and behavioral signs and symptoms of the disease as well as the care needed during each stage of the disease. Caregivers may require additional education and support about caring for themselves, as providing care to a patient with a chronic, life-limiting illness can be physically and emotionally challenging. Many educational resources such as books, patient/family education materials, articles, websites, are available through the local and national Alzheimer's Associations.

Education materials should be provided in a format the caregiver prefers and is able to comfortably use. Some caregivers learn best by using printed materials, others may be able to utilize internet sites or video/DVD information. All education materials should be accompanied by your verbal instruction, explanation and encouragement. If the caregiver needs information not readily available to you, be sure to involve the Interdisciplinary Care Group in finding the appropriate person or resource for your family or caregiver.

Prepare to provide care to those affected by Alzheimer's disease and other dementia disorders by first educating yourself. Become familiar with or identify where to find caregiver education on the following topics:

- Clinical signs, symptoms, stages and progression of Alzheimer's disease and other dementia illnesses
- Communicating with and understanding the communication of the person with dementia
- Understanding and managing difficult dementia behaviors
- Managing ADLs (Activities of Daily Living) and other aspects of physical care
- Helping the caregiver to identify signs of "burnout" and self-care activities

- Making treatment choices
- Using alternative therapies: music, aromatherapy, storytelling, familiar ritual or other faith connections to provide comfort
- Making difficult ethical decisions including long term care placement, feeding tube placement or withdrawal
- Understanding, interpreting and executing advance directives
- Assisting in the decision to consider respite or long-term care placement
- Identifying safety concerns and providing safe and caring home supervision

MAKING DECISIONS

Patients and their families affected by dementia will need to address many important and often difficult decisions throughout the course of the disease. Healthcare professionals can assist patients and families with decision making by asking the important questions, listening to the answers and honoring patient and family goals and choices about advance directives, placement and other important issues.

It is best, but not always possible due to cognitive difficulties, for the patient to complete advance directives, appoint a power of attorney, determine a health care surrogate, complete a will and address financial issues early in the course of the disease. Advance directives should be as specific as possible, especially about nutrition and hydration, treatment of infections, and resuscitation. This allows the patient to have his/her wishes honored when they can no longer verbalize or advocate for those choices.

Overall, try to include the patient in the decision-making process as long as they are able. Even when the patient may not have the cognitive ability to make decisions about finances or a will, they may still be able to make decisions about what foods he wants for dinner, what TV channel or radio station he would like to listen to, and when he would like to go to bed.

If the patient can no longer make decisions due to loss of cognitive function, responsibility for decision making becomes more complicated and may fall to family members or a health care surrogate.

To assist the family members with decision making, provide education and information about the issue and encourage them to think about what the patient would have wanted for each situation. Did they express any wishes informally?

Think about the patient's belief systems, culture, values, religious preferences, fears in terms of care and treatment. What would the patient have wanted based on these influences?

Look at the pros and cons, the benefits and burdens of each treatment or procedure before making the decision. Will the treatment or plan of care cause more burden, risk or discomfort for the patient or will the treatment cause more benefit, comfort, quality of life for the patient? Think of burden and benefit in physical and emotional terms. Ask questions of knowledgeable professionals about the benefits and burdens. Take as much time as needed to come to a decision about important matters.

Remember that decisions may change over time. For example, an antibiotic for pneumonia may be requested while the patient is experiencing a good quality of life, but that the decision may be changed

to withhold antibiotics when the patient is no longer able to swallow and is in the final stages of the disease.

Some of the types of decisions that may need to be made include when to stop driving, making choices about aggressive vs. palliative care, CPR, DNR and living will stipulations, long term care options, funeral plans and autopsy requests.

DRIVING

Making the decision to no longer drive may seem a simple and obvious matter, but for the patient and family this decision is often extremely difficult. The ability to drive in this society signifies independence. While the goal is to allow patients to remain as independent as possible for as long as possible, a patient with dementia behind the wheel of a car places the patient, passengers and other drivers and passengers in danger. Often patients and family members will overestimate the person's ability to drive. Driving requires good judgment, the ability to make quick decisions, quick reflexes, mental alertness, and the ability to remember the locations of things such as the store, the doctor's office and even the location of one's home. Cognitive impairment and dysfunction affect all of these abilities.

When the diagnosis of dementia is made, there should be discussion about the patient's ability to drive. If the patient chooses not to quit driving and does not have the skills to drive, the car keys or car should be hidden, or the car disabled, to prevent injury to the patient and others. In addition, there are some states that require reporting of drivers with decreased ability to drive. In Florida, physicians, persons or agencies who know of any licensed driver's or applicant's mental or physical disability to drive is authorized to report this to the Department of Highway Safety and Motor Vehicles. The identity of the reporting person is kept confidential. The State of Florida, Department of Motor Vehicles also has a program called Florida Grand Driver which provides safety education, evaluation and information on aging and driving.

AGGRESSIVE VERSUS PALLIATIVE CARE

Aggressive care focuses on cure and prolonging life. Palliative care focuses on quality of life, comfort, dignity and compassionate care. The Alzheimer's Association's Ethics Advisory Panel suggests that efforts to prolong life in the advanced stage of Alzheimer's disease result in unnecessary suffering for people. In the panel's view antibiotics given to treat infections, cardiopulmonary resuscitation and tube feeding (for example) are considered life-extension technologies. The following treatment decisions may need to be considered during the course of care:

- Cardiopulmonary resuscitation (CPR)
- Artificial nutrition/hydration (tube feeding, IV fluids)
- Antibiotic treatment
- Hospitalization, invasive tests
- Medication administration (except for comfort)
- Dialysis
- Dietary restrictions (i.e., diabetic diets, sodium restricted diets etc.)

In a literature review on end-of-life care for nursing home residents with advanced dementia commissioned by the Alzheimer's Association, aggressive medical treatment for residents with advanced

dementia is often inappropriate for medical reasons, has a low rate of success, and can have negative outcomes that hasten functional decline and death. CPR is three times less likely to be successful in a person with dementia than in one who is cognitively intact. Those who initially survive are taken to an intensive care unit where most die within 24 hours (Volicer, 2005).

Because of the progressive decline associated with dementia, as well as the potential for moral dilemmas, it is important to educate the patient and family on options available to them in terms of aggressive and palliative care and the burdens and benefits of both. Many times, the patient may not be able to express their preferences for treatment. The health care surrogate decision maker(s) may need to determine what end of life wishes the patient previously expressed. The presence of a living will helps in making difficult determinations but applying a person's written wish to forgo antibiotic treatment in fact is not always easy for those involved. Overall, the more specific a Living Will is in terms of aggressive versus palliative care choices, the easier the decision-making process will be for the family in the later stages of the disease.

Open, culturally sensitive communication between family, caregivers, and the health care providers is essential to the provision of good care as a patient's health status changes and deteriorates. The palliative care plan for dementia patients at the end of life should reflect consideration of patient comfort and safety, and always include the treatment wishes of the patient whether expressed by the patient or by his/her advance directives and/or the input of the designated health care decision maker.

CPR AND DNR

In a patient's Living Will, they should specify when and if cardiopulmonary resuscitation (CPR) should be performed. If there is no Living Will, then the decision once again falls on family members/health care surrogate. If there is a Living Will and/or the family chooses no resuscitation, then a DNR (Do Not Resuscitate) order should be obtained from the physician.

With or without advance directives in place, ethical issues may still occur if a conflict arises between family members who are not comfortable with choices about those topics that are usually included in advance directives - the administration of food and fluids when the patient can no longer eat, the use of a respirator to help with breathing if the person can no longer breathe on his/her own, the use of antibiotics for life-threatening infections, and whether the patient should have a Do Not Resuscitate order if his/her heartbeat and breathing stop. If the patient is able to complete advance directives, encourage him/her to discuss and work out conflict about those choices with all family members before a Living Will has to be put into effect. Conflict in decision making can have underlying issues including family dynamics issues, feelings of guilt, fear of death, issues of loss and many other complicated emotional and spiritual factors that may require the assistance of a psychosocial and/or spiritual care professional.

SYMPTOM MANAGEMENT

As there is no cure for Alzheimer's disease, interventions center on physical and behavioral symptoms caused by cognitive impairment. The following types of care and interventions to manage patient symptoms reviewed below are:

- Medications

- Physical care
- Emotional, behavioral and spiritual care

Alzheimer's Disease Cognitive Treatment Medications

There is no cure for Alzheimer's disease, and current drug therapies act merely to sometimes delay symptom progression. Alzheimer's disease is the most common cause of dementia in people over the age of 65 with an estimated one in eight persons aged 65 and older affected with the disease.

There are currently only two types of medications approved by the U.S. Food and Drug Administration (FDA) for use in treating the cognitive symptoms of Alzheimer's disease. These medications work by affecting the activity of two different chemicals that are involved in carrying messages between the neurons.

Cholinesterase inhibitors help with cognitive function and memory by temporarily raising levels of acetylcholine. Acetylcholine is a messenger chemical that carries messages to other cells which affects memory, judgment and thought. Alzheimer's disease damages or destroys the cells that produce and use acetylcholine. A cholinesterase inhibitor helps maintain acetylcholine levels available, and in some cases may stimulate the release of acetylcholine or strengthen the way certain receptor neurons receive it. NMDA receptor antagonists regulate the activity of glutamate- a chemical involved in learning and memory to improve attention, reason, language, and ability to perform simple tasks

The U.S. Food and Drug Administration (FDA) has approved the cholinesterase inhibitor medications, donepezil (Aricept) rivastigmine (Exelon) and galantamine (Reminyl) for treatment of Alzheimer's disease. These drugs work by maintaining existing supplies of acetylcholine. Tacrine (Cognex), the first cholinesterase inhibitor has not been available since 2012 because of associated side effects, including liver damage. There is no evidence that combining these drugs is more helpful than taking any one of them, in fact, combining them would unnecessarily increase side effects.

People taking all three of these cholinesterase inhibitors show some improvement in memory and other cognitive function, but the degree of benefit is small and more than half of those in clinical trials showed no improvement. Overall, most studies indicated that these drugs may help slow progress of the disease for about 6 months to a year, although some individuals had substantially better results.

Memantine (Namenda), a NMDA receptor antagonist released for use in 2004, works in a different way – NMDA receptor antagonists prevent the excess entry of calcium ions into brain cells. Excess calcium in the brain cells damages them and prevents them from receiving messages from other brain cells.

Memantine (Namenda) is FDA approved for use in moderate to severe Alzheimer's disease. Memantine is not a cholinesterase inhibitor. It is considered a N-methyl-D-aspartate (NMDA) receptor antagonist. Glutamate, a messenger chemical, affects learning and memory. When there is too much glutamate, it triggers NMDA to release too much calcium into nerve cells and causes the death of those neurons. Memantine works by partially blocking NMDA receptors to protect against the release of too much calcium.

Memantine has been used in Germany for over 20 years and is approved for the treatment of moderate to severe Alzheimer's disease. Clinical studies in the U.S. has shown delay in the deterioration of basic functions, such as the ability to go to the bathroom independently, feed oneself with less mess and perhaps be less easily distracted.

These modest benefits may help a person to delay nursing-home placement for a period of time. (Abramowicz, 2003). There is some evidence that combining memantine with one of the cholinesterase inhibitor medications may benefit some patients with moderate to severe Alzheimer's disease.

Medications currently recommended for use in the treatment of cognitive impairment due to Alzheimer's disease:

Donapezil (Apricept)

- For treatment of all stages of Alzheimer's disease
- Improvement in cognitive function or no change in 80% with Alzheimer's disease (as compared to a decline in control groups) improvement in 35-60%, no change in 20-45%
- Benefits seen in up to 2 years of treatment
- Return to control group function in 3-6 weeks after stopping the drug
- Well tolerated with no alteration in liver function tests Dosing/side effects
- 5 mg/day initially; increase to 10 mg/day after 4-6 weeks as tolerated
- Dose related side effects: nausea, diarrhea, insomnia or agitation
- Available in tablets and orally disintegrating tablets which dissolve on the tongue

Rivastigmine (Exelon)

- For treatment of mild to moderate Alzheimer's disease
- Improvement in 25-30% of patients at 6-12 mg/day
- Improvement maintained for about 1 year before declining
- No liver toxicity
- Dosing/side effects
- 1.5 mg. 2 times daily, may increase every 2 weeks to 12 mg. total daily
- Available in capsule, liquid, and transdermal patch
- Take with food to minimize gastrointestinal side effects of nausea, vomiting, diarrhea, abdominal pain and loss of appetite

Galantimine (Razadyne)

- For treatment of mild to moderate Alzheimer's disease
- Superior to placebo at 16 mg/day
- Improvement sustained 6 to 24 months
- Avoid in patient with liver or renal impairment
- Dosing/side effects
- 4 mg. twice daily to start, may increase after 4 weeks to 8 mg. twice daily to 16 mg.
- Take with food
- Most common side effects: nausea, vomiting, diarrhea, loss of appetite, weight loss, dizziness, may slow heart rate
- Available in tablet, liquid extended relief capsule
- If therapy is discontinued more than several days, medication should be not be restarted at previous level, but titrated again from starting level

Memantine (Namenda)

- May work at more advanced stages of Alzheimer's disease
- Memantine (Namenda) released for use in 2004 works in a different way than cholinesterase inhibitors.
- It prevents the excess entry of calcium ions into brain cells.
- Excess calcium in the brain cells damages them and prevents them from receiving messages from other brain cells.
- Memantine has been approved for use during moderate to severe stages of Alzheimer's disease.
- May delay deterioration of basic function, such as self-feeding, toileting, decreased agitation in some people
- Dosing/side effects
- Start 5 mg/day; increase by 5 mg/day at weekly intervals to maximum of 20 mg/day. Divide daily dose when over 5 mg/day
- Most common side effects: headache, constipation, elevated blood pressure, confusion and fatigue
- Can be taken with or without food
- Available in tablet and liquid solution

Memantine /Donepezil (Namzaric)

- Approved in 2014 by the FDA
- Used for moderate to severe stages

Florbetapir is a new radioactive drug has been FDA approved for use with PET imaging to visualize amyloid plaque buildup in the brain. This may be helpful in ruling out Alzheimer's disease. If a person does not have plaque buildup, the cause of the cognitive impairment is likely something other than Alzheimer's. If plaque is present, it may or may not indicate the presence of dementia or Alzheimer's. There are no clinical recommendations on the use of Florbetapir for PET imaging yet and testing will continue as ways to best use this drug are further explored.

PHYSICAL CARE INTERVENTIONS

As disease progresses, patients will require increased assistance with ADLs including toileting, bathing, grooming, dressing and feeding. In addition, nutrition and hydration will need to be monitored throughout the course of the disease.

Toileting

On admission, it is important to get the patient's and family's input about toileting habits so that the patient's toileting routine can be maintained for as long as possible. History about elimination is also helpful in anticipating elimination problems and toileting needs.

In the early stages, a patient may need very little help with basic activities, including toileting. Encouraging fluids is important to help with hydration. Monitoring and asking with gentle reminders may be helpful, and assist as needed.

In the middle stages of the disease, the patient may be continent but have difficulty remembering the location of the bathroom or remembering to empty his/her bladder. As time goes on, they may have difficulty with the toileting process such as pulling down his/her pants, sitting on the toilet, wiping and

flushing. Some ways to maintain independence in toileting for as long as possible may include using signs to help the patient locate the bathroom, gentle reminders about using the bathroom, and assistance with breaking down the steps of the toileting process.

In the late stages of the disease, the patient will become incontinent and/or no longer respond to cuing to use the bathroom. Assess the patient to rule out other causes of incontinence such as existing medical conditions, medications, bladder stimulants like caffeine, stress incontinence, functional losses, and neurological damage.

When the patient becomes incontinent, incontinent products may be needed. Initially placing underwear over the incontinent product may make the transition more acceptable to the patient.

Bathing, Grooming, Dressing

During the early stages, encouraging choice of clothes and allowing patients to dress themselves may be an important aspect to their independence and how they see themselves. Likewise with bathing and grooming, providing tools when needed can be helpful, and monitor for safety and comfort. Consider that new medications may cause constipation or other continence-related side effects that could affect an otherwise established routine.

In the middle stages, bathing, grooming, and dressing begin to prove a greater challenge for the patient. The loss of privacy and independence during this stage can be an intense, difficult transition for both the patient and the caregiver. Consider interventions such as giving direction as needed, laying out clothes in the order in which the item is put on, providing favorite grooming tools, and staying flexible.

Performing tasks alongside a patient can also be helpful; when it comes time to brush hair, comb through your own hair while encouraging the patient to copy your motions.

As the disease progresses, bathing, grooming and dressing become more difficult for the patient. The patient may need assistance entering or exiting a tub or shower, adjusting water temperature, or washing and drying themselves. In addition, they may be fearful of the water. The patient may have difficulty locating his/her clothes, have difficulty making decisions about what to wear, forget to change clothes, or change clothes repeatedly throughout the day. They may resist removing clothing at bath time or at bedtime. As confusion increases, the person naturally feels more threatened in what seems a continually changing environment and naturally resists what they sense as unfamiliar in a world which they can no longer trust. Imagine if you found yourself in an unrecognizable room with strangers who insist that is time for you to take off your clothes. In the later stages of the disease, the patient will need total care. The following interventions may help the patient remain as independent as possible for as long as possible:

- Maintain the patient's original bathing, grooming and dressing routines for as long as possible. If no longer possible, try to create a routine such as bathing and then dressing right after breakfast.
- Minimize distractions. Speak with kindness and patience. Be respectful.
- If the person seems embarrassed, wrap a towel around them or use a loose fitting, light weight shirt or hospital gown to help minimize exposure.
- Provide step by step coaching as needed, breaking down the instructions to one step at a time. Avoid lengthy discussions about the need for a bath.
- Only help when the patient needs it.

- Perform bathing and grooming tasks with the person. Use liquid soap and a large soft sponge to make bathing quicker and easier.
- Give the person a washcloth to hold, even if they are unable to assist in bathing.
- Play soft music to create a calm environment, try lavender or other comforting aromas if appropriate.
- Reduce clothing choices to one or two outfits.
- Simplify clothing to those items with Velcro rather than buttons or snaps, to slip on shoes instead of tie shoes.
- Prompt the patient to change clothes when needed. Gently direct the patient rather than asking them. "Janet, let me help you put on this pretty shirt."

As the patient's condition deteriorates, assessing the home for safety concerns should be periodically performed. For instance, a restless patient may turn on appliances so knobs may need to be removed from the stove. Cleaning supplies, medications or other potentially poisonous materials need to be stored safely away. The hot water heater should be adjusted to prevent burning while washing or bathing.

Nutrition and Hydration

In the early stages, encouraging fluids is important to aid with hydration, and continuing to encourage choice, variety, and assessing safety is important. Asking if they are hungry or would like a snack can be helpful when monitoring.

As the patient's condition declines, nutrition may become more difficult to maintain. The patient may forget to eat, forget how to eat, or may not be able to recognize hunger or thirst. Dehydration can occur at any time during the disease. The patient may forget where fluids are located, have difficulty pouring from a water pitcher or may no longer understand how to use a water pitcher. If water fountains are available, the patient may not remember how to use them. In the late stage of the disease, the patient may have difficulty swallowing. To maintain adequate nutrition and hydration, the following interventions may be helpful.

- Minimize distractions during mealtimes.
- Assist with feeding as needed. Cue the person verbally if needed. "Here's some sweet potato." "Don't forget to swallow." Cue the person visually, sit in directly in front of them, open your mouth, chew, etc.
- Offer favorite foods. Offer ice cream, milkshakes or flavored dietary supplement drinks to boost calorie intake.
- Avoid busy patterns on plates or tablecloths.
- Provide extra calories to those with increased physical activity from restless pacing.
- Try to keep the eating process as independent and easy as possible by de-boning meat, opening containers or packets of butter or condiments, loosening napkins, and serving soup in cups instead of bowls.
- Provide finger foods to help maintain independence, even severely impaired patients can often manage finger foods.
- Watch for misuse of utensils, visual neglect of one side of the tray, confusion over the number of foods on a tray, difficulty with decisions about what to eat first and

swallowing difficulties. When a knife can no longer be used appropriately, precut and preseason all food and provide only a fork and spoon.

- Use bowls or plates that are brightly colored so the person can easily locate the plate.
- Avoid offering very hot foods and liquids.
- For cold liquids, use cups with lids and bendable straws or “sippy” cups to make drinking easier.
- Try offering frequent small meals with snacks available.
- When swallowing becomes difficult offer small bites one at a time and remind the patient to swallow after each bite. Provide pureed and thickened foods, and increased protein and supplements to maintain nutritional status.
- Provide and encourage fluids as much as possible to prevent dehydration.

LEARNING ACTIVITY

Communicating simply and completely is often the key to assisting Alzheimer’s patients with tasks. Think about the number of steps it takes to put on your pants? As though you were coaching a patient in the early to middle stages of Alzheimer’s disease, break down the instructions to one step at a time to help him put on his pants, shoes and socks.

EMOTIONAL, BEHAVIORAL, AND SPIRITUAL CARE

When a diagnosis of Alzheimer’s disease or other dementia is made and throughout the course of the disease, patients as well as their caregivers will be affected by an array of emotional, behavioral and spiritual issues, changes and symptoms. The interdisciplinary group will do a complete and ongoing psychosocial assessment and implement interventions and strategies to manage symptoms to improve quality of life for the patient and family. It is tempting to assume the person with dementia who has limited ability to understand language and speak in a meaningful way is childlike in their understanding. A toddler who is learning to talk often understands a great deal more than they can express. In this way dementia patients may be similar. But an adult is more adept at understanding than a toddler. An adult with dementia has a lifetime of learning and understanding concepts, behaviors, body language and other skills associated with communication. The patient may understand a great deal more than you assume. But, they will need more time, need more cues and more patience to understand what others are saying and be able to express themselves. Imagine that you are aware that others find you frustrating and they suddenly treat you as though you are a small child or worse, that you are stupid, and that you can’t communicate that you are still your old self inside and aren’t ready to be discounted. The anger and frustration a person with dementia feels may often be perfectly understandable. Our compassion, care, and respect for any person with any end stage disease should be consistently provided. Take time to put yourself in the place of the person with the disease of dementia, with one in five adults over age 65 affected, you may one day get to experience the care you provide.

Depression, Anxiety and Agitation

At the time of diagnosis and throughout the disease process, patients with dementia as well as their caregivers may experience anxiety, depression and even contemplate suicide. Patients can have a history of depression or other mental illnesses prior to and independent of dementia, so it is important

to do a complete health history, including a history of mental illness with a focus on anxiety, depression and suicidal ideations.

The changes in thought and understanding, in visual and spatial reasoning can leave the dementia patient with tremendous anxiety about the world around them. As their ability to trust what they see, hear and understand diminishes, they will very likely experience fear, even panic at times. Imagine finding yourself in a strange environment, with people you think you know, but can't quite remember. These people are telling you things you don't quite understand or that you forget. You remember clearly some things, but other thoughts elude you.

Anxiety is a most appropriate feeling for people in this situation. Symptoms of depression are not surprising when you consider the losses experienced. The ability to perform sequencing tasks which encompass the basic functions of an independent life with reliability, are a first major loss (paying your bills, balancing the checkbook, making a familiar recipe). We all have roles and abilities that we use to define ourselves. You are a mother/father, a nurse, you have a green thumb, you can cook, you are Muslim, Greek, blonde, tall...all these associations are eventually lost in the malfunctioning brain. The loss of the things that identify a person as unique, their memories of the past and hopes for the future slowly fail.

In the patient with dementia, symptoms of anxiety can include repeatedly calling out for help, pacing, and hand wringing as well as other behavioral symptoms. While anti-anxiety medications may be helpful, they can also cause sedation and may have side effects that actually increase agitation and sometimes rage reactions. Symptoms of depression are extremely common in dementia due to both cumulative loss reactions and brain neurotransmitter changes. Exercise and activity along with medication management can improve function, mood, irritability and mood swings. Medications with limited anticholinergic side effects such as citalopram, sertraline, fluoxetine, paroxetine or fluoxetine (selective serotonin reuptake inhibitors or SSRIs) can be helpful in treating depression.

They have fewer side effects than the older tricyclic antidepressant drugs and are safer for use in elderly patients. Side effects that may occur in the first few weeks of treatment with SSRI medications include headaches and mild nausea or diarrhea. Keep in mind that in a nursing facility, the use of psychiatric treatment and the use of antipsychotic and anti-anxiety medications is monitored and regulated. They are not to be used unless symptoms and an appropriate diagnosis indicate use of these medications. The physician and/or psychiatrist should evaluate the patient and provide an appropriate diagnosis, and all members of the interdisciplinary team should document behaviors related to anxiety and symptoms related to depression. In the residential care setting using a psychotropic medication to sedate or control a patient who has verbal outbursts is not appropriate unless there is evidence that this is causing some harm. This use may be a form of restraint limited by federal and state regulations governing nursing home and assisted living.

The use of major tranquilizers in people with dementia is sometimes prescribed to treat symptoms including agitation, combativeness, aggression and delusions but has not yet been determined to be effective. Side effects including excessive sedation and dizziness can be dangerous and only used if the person is under constant supervision. Using a tranquilizer to control behavior at the expense of a person's mobility and alertness is questionable ethically. The newer generations of major tranquilizers (including risperidone and olanzapine) which may have fewer side effects are contraindicated for use in people with dementia because of increased incidence of stroke.

Medication Management Insomnia

- Assess for and treat underlying causes (such as depression or “Sundowning”)
- Avoid benzodiazepines (Ativan or Xanax) that can exacerbate sleep apnea and cause rebound insomnia and worsening cognitive function
- Avoid diphenhydramine formulations (over the counter “PM” nighttime sleep aids) which can cause anticholinergic delirium in the elderly
- Zolpidem (5 – 10 mg nightly)
- Trazadone (25 – 100 mg) as needed nightly

Psychosis and agitation

- Assess why now – is this a new medical problem, change in environment, depression, constipation? Consider all non-drug interventions first.
- Use the “start low, go slow” adage in dosing and regularly reevaluate need for continuing use.
- Use antipsychotics, such as risperidone, haloperidol (.5 – 2.0 mg/day), olanzapine cautiously and only if patient can be monitored
- Save benzodiazepines (such as lorazepam – trade named Ativan - which has low active metabolites) for special needs such as change in location or symptoms of panic attacks. Regular use results in ineffectiveness as a sedative and anxiolytic and risks worsening disinhibition.

With or without the use of medications, it is important for the interdisciplinary team to initiate non-pharmacologic interventions to decrease anxiety and depression. It is always better to determine the underlying cause of the outburst (e.g.: pain, fear, loneliness) and work to resolve that issue. Calming interventions such as music, a back rub, a quiet and reassuring voice should always be the first response to a person with dementia who is upset. The involvement of psychosocial and spiritual care providers is essential. Volunteers can provide companionship and diversion for the patient. In addition, involving the patient in meaningful activities may help alleviate some of these symptoms.

Behavioral Symptoms

Behavioral changes and symptoms are a major issue for many of those caring for patients with dementia disorders. Behavioral changes can be emotionally challenging for family members/caregivers and professional staff.

Establishing relationships and treating patients with respect and dignity are the first steps in managing behavioral changes and providing compassionate care. Establishing and maintaining a relationship with the patient requires that family, caregivers and staff assess the behavior, try to understand the patient’s abilities to communicate and behaviors used to communicate. When behaviors are viewed as forms of verbal and non-verbal communications and when it is understood that all behavior has meaning, care providers are better able to respond to patients in sincere, warm, non-judgmental ways.

Assessment

When behaviors change, it is important to assess the patient and situation to identify the problem and etiology behind the behavior change. This should be done before initiating interventions. To assess behavior, ask yourself the following questions:

- What is the behavior? (hitting, crying out, arguing etc.)

- Where does the behavior most frequently occur? (in the bathroom, the car)
 - Is the behavior triggered by something, someone, the environment?
 - Is the behavioral change consistent with the level of cognitive impairment?
 - Is the behavior change due to the disease process or is it triggered by something else?
- Keep in mind that behavior changes can be caused by:
- Physical discomfort from pain, illnesses or medications
 - Over-stimulation from too much noise or activity in the environment
 - Unfamiliar surroundings and the inability to recognize where they are
 - Complicated tasks with too many steps that cause frustration
 - Frustrating interactions due to inability to communicate effectively

Stages of the disease process with corresponding behavioral changes to help you identify behavior changes consistent with Alzheimer's disease are as follows:

Early Stage Behavioral Changes

- Repeating questions or statements
- Difficulty performing familiar tasks (including use of appliances)
- Irritability
- Stubbornness
- Impairment of judgment (losing or giving away money)
- Wandering, getting lost
- Difficulty finding words, initially speaking more to cover confusion and then speaking less
- Misplacing items, accusing people of stealing
- Loss of initiative

Middle Stage Behavioral Changes

- Increased confusion about recent events
- Suspiciousness and paranoia, resulting in accusation
- Hallucinations
- Sundowning (increased agitation in late afternoon/evening)
- Resisting assistance with personal care (grooming, bathing, dressing)
- Hoarding and rummaging
- Wandering, searching for home
- Repetitive movements or statements

Late Stage Behavioral Changes

- Unable to use or understand words
- Repetitive vocalizations (moaning, crying out)
- Inability to recognize close family members
- Difficulty recognizing care providers, resulting in resistance to care

GENERAL INTERVENTIONS FOR COMMUNICATION AND BEHAVIOR MANAGEMENT

General Interventions to help communicate effectively with the patient and manage behavioral symptoms are as follows:

- Listen carefully to verbal cues and observe non-verbal communications and behaviors.
- Stay calm, be patient and assess the situation to try to determine the cause for the change in behavior.
- Be flexible.
- Respond to the patient's feelings.
- Avoid arguing with, confronting, or trying to force the patient to change behavior.
- Reasoning will rarely be helpful.
- Avoid giving the patient insight into his/her behavior. Accept the behavior and try to work through it.
- Avoid the use of negative reinforcement to try to change the patient's behavior. Negative reinforcement involves the removal of a negative condition to strengthen a behavior; a stimulus is removed, the behavior increases or reinforced. Think of it as taking something negative away to increase a response.
 - For example, nagging at a patient until a specific task is complete. Once they complete the task, the nagging stops.
- Maintain genuine, comfortable eye contact if appropriate. Don't stand over the person as this can be intimidating; approach them at their eye level or below to convey respect.
- Use a clear, soft and caring voice tone.
- Use touch as appropriate and comfortable for the patient.
- Look for the good in the patient. Note the patient's ability to care about others, experience feelings and emotions, demonstrate specific skills, enjoy different kinds of interactions, be redirected. Focus on these abilities to manage behavioral symptoms.

The ABC Model is a behavior management technique that can be used to track and analyze challenging behaviors in order to find new ways to approach and responds to them.

There are three parts of the ABC model:

- A – antecedent: anything that happens before a challenging behavior, and may be the catalyst for the behavior
- B – behavior: the observed action that is in response to an activating event and generates an undesired consequence
- C – Consequence: events that occur immediately after the behavior; this can be dependent on staff's reaction to the behavior. A consequence that is ineffectively or inappropriate managed may become another activating event that triggers the cycle.

Often, behavioral problems can be addressed with properly trained staff, and this problem-solving approach can be very effective when insights from the ABC Model is shared between the healthcare teammates, caregivers, and family members. These insights help provide a context for the behavior, which in turn allows caregivers – professional and familial – to discuss and evaluate the catalyst and consequences, and which interventions need to take place and when.

SPECIFIC BEHAVIORS AND INTERVENTIONS

Specific behaviors may require more specific interventions. Specific disease-related behavioral changes can include:

- Forgetfulness and disorientation
- Sleep disturbances
- Repetitive behaviors
- Hoarding and rummaging
- Suspiciousness and paranoia
- Exit-seeking behavior
- Angry and agitated behavior

Forgetfulness and Disorientation

Patients with Alzheimer's disease and other dementia disorders often forget people and places once familiar to them. Instead of arguing with the patient about time, place and person, try to help the patient by identifying people and places for them. For example, you might say, "Isn't it good to see Jane?" or "Let's go into the dining room."

Sleep Disturbances

Patients with Alzheimer's disease have a high incidence of sleep disturbances, including "sundowners" syndrome. Sleep disturbances can be caused by sleep apnea, medications, lack of exercise during the day, napping too much during the day, drinking too much with the need to get up to urinate at night, and the disease process. To help the patient sleep at night, try engaging him/her in meaningful activity and exercise during the day. Provide outdoor time or place the patient in a sunny room with natural light exposure for part of the day. Limiting fluid intake prior to bedtime may also help the patient sleep better at night.

Repetitive Behaviors

Often patients with Alzheimer's disease will repeat words, phrases and actions over and over. Repetitive behaviors are triggered by a combination of short-term memory loss and anxiety or boredom. Sometimes the repetition may have meaning to the person and be related to a former job or activity. In most cases, this behavior bothers others more than it does the patient. For repetitive behaviors, respond in a caring, consistent manner. Don't scold or ridicule the patient, and don't discuss future plans in advance. Plan enjoyable activities to distract the patient or try turning the repetitive action into an activity.

Things that may be helpful:

- Stay calm and be patient. Speak slowly and use simple words and short sentences.
- Turn the action or behavior into an activity. If the person is picking at their clothes; offer a stack of wash cloths to fold. Involve them in exercise. Bring them a pet to stroke. Turn on some music.
- Distract the person by providing them a rummage box. A rummage box is a small container with an assortment of items that are easy to manipulate and have interesting

textures or content. Familiar items such as spoons, a tape measure, sponge, ribbons, gloves, photographs etc. make good items.

- If they repeatedly ask a question, such as “What time is the wedding?” give them the answer even if you have to repeat it several times.
- Look for a reason behind the repetition, accept it and work with it. Anxiety about missing the upcoming event might prompt repeated questioning. Help them by providing a calendar or put up reminder notes.

Things that will not be helpful:

- Telling the person you have already answered their question a dozen times
- Ignore them

Hoarding and Rummaging

Patients with Alzheimer’s disease may spend time searching for, accumulating and hoarding items. Rummaging and hoarding are often more disturbing to family members and other caregivers than it is to the patient. Before intervening, remember to think about who is being negatively impacted by the behavior -- you or the patient? It should be noted that hoarding and rummaging can be a hygiene problem if the patient hoards soiled clothing or perishable items. To manage this type of behavior, you can:

- Plan rummaging-type activities. (provide a stack of magazines with safety scissors to cut out pictures)
- Design a plan for putting things away or returning things to others.
- Busy their hands with other tasks and projects or simple games.
- Avoid scolding or mocking as this and other behaviors are meaningful to the patient.

Suspiciousness and Paranoia

This type of behavior may be an exaggeration of the person’s underlying personality or a way of making sense of a confused reality. They may accuse you and others of stealing, cheating or lying. Patients often hide objects in strange places and then forget the location. This prompts them to suspect someone has stolen it. Because they have difficulty understanding and processing information, they can misinterpret a conversation and while what they remember is inaccurate, they are convinced what they recall is true. For this type of behavior:

- Remain calm and don’t argue with the person.
- Offer reassurance that you will help look for what is lost.
- Do not take accusations personally.
- Respond to the feelings expressed and offer a reassuring response.
- Do not argue with the patient.

LEARNING ACTIVITY

The patient accuses you of stealing his sweater. The patient’s wife asks if you stole the sweater. How would you best respond to the patient and the patient’s wife?

Exit Seeking and Wandering Behavior

Patients who wander or experience exit-seeking behavior may have a history of active living and independence or a history of exiting or leaving a place or person when they experience stress. Sometimes the environment is cuing the wandering. For example, a patient that is bored may leave in an attempt to find a more stimulating environment elsewhere. A patient who needs to use the bathroom but cannot find it may leave in an attempt to locate a bathroom.

Wandering is frightening for the caregiver and poses risks of injury to the patient. To help limit exit seeking behavior and wandering consider the following suggestions.

- Identify patterns and time frames for wandering.
- Find safe areas where the person can walk.
- Put on some music and encourage the patient to dance or move with the rhythm. If they played an instrument, encourage them to play. The ability to play an instrument and sing lyrics to songs is often retained longer.
- Keep recent photos of the patient on hand with a written description of hair color, eye color, jewelry they usually wear and any other identifying information unique to them.
- Mark anything the patient routinely wears with identifying information, such as eyeglasses and shoes.
- Keep items with the patient's scent as there are now canines that can assist in finding a person if they have a scent to trail.
- Alter the environment to provide additional safety. Locks for doors should be out of the line of vision and out of reach of the patient. A security system that beeps or rings when a door is opened is also helpful. Place baby monitors in rooms the patient frequents so the caregiver can track the patient's whereabouts.
- Consider the Safe Return program from the Alzheimer's Association. This program offers ID bracelets, registration in a data base to report someone missing, and labels for the patient's clothes as well as additional information on wandering.

Agitated and Angry Behavior

Watching for symptoms such as restlessness that preclude these behaviors and intervening early may prevent more severe reactions. People who have impaired or limited emotional response resources may display anger as it is their most accessible and reliable emotional reaction. Angry and aggressive behavior can manifest in shouting, screaming, even kicking and biting. It may be triggered when the person is unable to identify the people around

them or when they can't figure out what someone is saying or wants. It may be a reaction to feeling humiliated or frightened. They may be bored or tired. Often the reaction seems out of proportion to the cause. A person with dementia lacks the sound judgment skills and normal social inhibitions on aggressive behavior and does not remember how to behave correctly. Try to avoid placing the patient in situations or conditions that might trigger this type of behavior.

- Avoid having too much noise, activity or people around. Too much input increases the sense of stress and pressure as a person finds they are no longer able to meet the demands of daily life.
- Be patient when they are adjusting to a new place or people. They can become frightened and bewildered in new situations. They may be convinced they are in the wrong place or that someone new is dangerous.

- Allow extra time when preparing for bath time or changing clothes. Independence and privacy needs are threatened when a person needs to be helped in daily intimate functions.
- Be alert for signs the person needs to use the restroom, is hungry or too tired.
- Don't ask them to do more than they can do. The sense of failure and humiliation at feeling judged or criticized for inability to understand can evoke an angry response.

Things you can do to help the agitated patient:

- Stay calm and use a gentle tone of voice. Sharp, loud voices can trigger more extreme reactions.
- Approach the patient from the front to prevent startling them. Approaching them from behind can startle them.
- Break down what you want them to do in simple, easy steps.
- Say comforting words, "You're safe." "I will stay with you." "I'm sorry you're upset."
- Listen and try to understand.
- Check for pain, hunger, thirst, fatigue, full bladder or constipation or soiled underclothing.
- Try to redirect. Offer the distraction of an activity, ask the patient if they would like to take a walk
- Try the activity later or reschedule bath and dressing times to accommodate the person's daily tolerance and personal preference.

Things that are not helpful:

- Raising your voice or using a patronizing tone.
- Trying to reason, argue or contradict.
- Trying to grab or corner the person who is moving away.
- Allowing the person to hurt your feelings or upset you. They have no control over your feelings, only you do.

Hallucinations and Delusions

Hallucinations are imagined sensory perception. Seeing, hearing, smelling, tasting or feeling things that are not really there are hallucinations. Delusions are imagined thoughts or ideas. Thinking that someone may be spying on them or wants to harm them are examples of delusions. Not all Alzheimer's disease and other dementia disorder patients experience hallucinations or delusions. Visual hallucinations are most common in Alzheimer's disease patients who may report seeing people or things that are not there. They misinterpret the visual signals the brain sends and may have difficulty recognizing themselves in the mirror, see faces they think are real in the wallpaper, or think that paintings are real scenes. They may also be convinced that they are hearing voices or other sounds.

Distraction and reassurance can be helpful. Trying to correct the patient's perception will not help them, and only cause them to feel more suspicious and misunderstood. Let them know that you understand how upset they must be and offer to help and then redirect them into another area or new activity.

Most people seek a purposeful and meaningful life, and cognitively impaired patients are no exception. Involving the patient in work, leisure, personal care and spiritual care activities can help patients find

meaning and purpose in life, foster self-esteem and self-worth, and encourage self-expression and interactions with others.

Whether the dementia patient resides in long-term care, assisted or residential facilities or their private residence, they need to remain as active as possible for as long as possible. Activities for Alzheimer's patients require creativity and the ability to tie the activity to those things the patient enjoys or may find meaningful. Facilities usually have activities departments to create activities, but in a home care setting the family member/caregiver may need assistance in involving the patient in meaningful activities.

ACTIVITY FOR ALZHEIMER'S PATIENTS

When planning activities or when helping a caregiver plan activities, you should:

- make the activity part of the daily routine.
- make the activity as failure free as possible.
- focus on enjoyment, not accomplishment.
- stress involvement but not cause stress.
- avoid precise rules and be flexible about participants following the rules.
- consider the patient's prior abilities and skills.
- have a purpose in mind for the activity, such as an activity for the purpose of exercise or fun.
- individualize the activity as much as possible.
- be flexible.
- create activities that appeal to adult interests.
- be respectful of all participants.
- incorporate the life history and interest of the person.
- consider time of day, age, stage of disease.
- avoid over-complexity.
- minimize distraction.
- have an environment that encourages activities.
- remember that completing the activity is not as important as participating in the activity.
- provide positive input through praise and complements for any achievements.
- create a variety of activities.

Overall, everything a person does is an activity. Activities can fall into the domain of leisure, work-related, personal care, and spiritual care. Activities pertaining to these categories are listed below.

Leisure Activities

Leisure activities are those the patient finds fun or enjoyable. When planning this type of activity, explore the interests, activities and hobbies that the patient enjoyed before becoming ill. Try to match or modify activities to meet those interests. Some simple activities that might be enjoyable for the patient include singing, reading aloud, or simple cooking such as baking a cake from a mix, squeezing oranges for juice or making sandwiches. Patients may also enjoy painting, simple craft activities, feeding the birds, viewing birds and other wildlife, or arranging flowers in a vase. Just like most of the general population, patients with dementia may have a need to be outside. Outside activities such as gardening

or taking a walk can meet this need. Also remember that time outdoors may help patients sleep better at night.

Art as a leisure activity can help foster self-expression. In fact, art projects are a wonderful way for a person to express feelings. When a person has difficulty communicating in words, creating art is a way to express emotions. Simple art supplies such as water-based paints, sponge brushes, tissue paper, crayons, glue and scissors, can be kept together for quick projects to share with family and friends. Keep in mind that the use of scissors or cutting implements in art activities may need to be monitored.

Music is a way to combine various activities. Playing music specific to the generation of patients may encourage reminiscing. It may also help with long-term memory when the patient remembers the lyrics to songs or events that took place when the song was first released.

Dancing to the music allows the patient to reminisce while doing physical exercise. Anytime you provide or use music for patient and family care, be sure to find out what music they prefer. Find out if the patient played an instrument or enjoyed singing. The ability to play an instrument and remember lyrics is retained in most patients even after severe memory impairment is onset.

Work Related Activities

Many people find meaning and purpose in work. Patients with dementia may still find meaning in work, and/or have a need to be needed or helpful. The following work-related activities can help the patient feel useful and involving the patient in these types of activities can be helpful to the caregiver.

- Clipping coupons
- Raking leaves
- Sweeping the porch
- Planting seeds
- Folding clothes or towels
- Sorting socks
- Washing and putting away silverware
- Sorting coins
- Rolling yarn into a ball
- Feeding the fish, dog, cat
- Dusting

Personal Care Activities

Personal care activities such as bathing, grooming and dressing have been discussed earlier in the module. Physical exercise, such as walking or throwing a ball to the dog is activity that can be enjoyable as well as beneficial to the patient.

Spiritual Care Activities

Spiritual care activities can be those in which the patient finds meaning and purpose in life and death, and those that are part of a patient's spiritual or religious belief system. Patients may find a sense of inner peace by participating in spiritual care activities.

Many of the above activities could provide spiritual comfort for the patient such as viewing the birds, gardening, art and music. Other spiritual care activities that might be meaningful include:

- Reading spiritual material
- Listening to inspirational or liturgical material
- Life review and reminiscing, verbally or by looking at photo albums, family movies, etc.
- Life review by listening to a family member/caregiver talk about the patient's life and/or their life together
- Praying
- Singing or listening to sacred music
- Attending faith-based programs or rituals
- Watching or listening to faith-based recordings

Group Activities

Socialization is important for those experiencing Alzheimer's and related dementia diseases. They can decrease feelings of loneliness, isolation, and improve both mood and engagement. Providing a sense of belonging can decrease depression and anxiety, but it's important to consider the type of activity and how the content engages the patients. Activities that can be self-paced but also social excel.

For example, in the early stages:

- Singing:
 - sing familiar songs, choral activities, sing-a-longs
- Cooking:
 - Baking, preparing snacks for the group, decorating cookies, cleaning up afterward
- Outdoor activities
 - nature walks, park outings, berry or apple picking
- General outings
 - Going out shopping, visiting museums, libraries, and theaters, eating lunch at a restaurant
- Crafts and other hands-on, creative activates
 - Decorating for a holiday, creating a card for family, writing a letter, painting, ornament and other keepsake creation

For example, in the middle stages:

- Singing:
 - Focus on familiar songs
- Cooking:
 - Participating in baking, assisting in cleaning up
- Outdoor activities
 - Shorter walks, enjoying the park with a picnic
- General outings – similar to early examples, but adjusted and with more supervision
 - Going out shopping, visiting museums, libraries, and theaters, eating lunch at a restaurant
- Crafts and other hands-on, creative activates
 - Assisting in decorating for a holiday, dictating a letter, participate in painting, ornament and other keepsake creation

For example, in the later stages:

- Singing:
 - Listen to music, sing along as able
- Cooking:
 - Decorating baked cookies, eating the created confections together
- Outdoor activities
 - Escorted walks or wheelchair outside, attending a picnic
- General outings
 - Watching movies together, setting up a store, café, or other small shops for patients to attend, outings with direct supervision
- Crafts and other hands-on, creative activities
 - Assisting in decorating for a holiday and other parties or smaller gatherings, participate in painting, ornament and other keepsake creation

The Therapeutic Environment

Providing a safe and comfortable environment is everyone's responsibility. Patients with dementia should be treated with dignity and respect. Privacy should also be respected in bathing, grooming and in dealing with challenging situations. Because dementia patients often experience poor judgment, memory loss and physical decline, safety is an issue. To prevent falls, the physical environment should be calm, uncluttered, well lighted, secure and as familiar as much as possible.

People with dementia are prone to experience behavioral changes, mood swings and sometimes aggressive behavior. The sounds of bells, buzzers, alarms and overhead paging systems in long term care facilities, hospitals and doctor's offices can trigger agitation, irritability and increase confusion. A loud television or a noisy room can cause irritation. Changes in the environment, such as moving furniture, moving the patient's room, changes in staff, and changes in daily routines may also be reflected in negative behavior. Keeping the environment as soothing and calm as possible can help prevent emotionally charged situations. Soft melodic music, warm lighting and familiar aromas can create a pleasing space that encourages participation and involvement in activities.

The Outdoor Physical Environment

As Alzheimer's disease progresses in a patient often access to the outside world declines. This is often a response to maintaining safety. A person with dementia who wanders is not safe alone outside. However, there is benefit to the exercise and stimulation provided in the outdoor physical environment.

To support outdoor activities, it is important to plan ahead. Examine mobility and safety needs, and obstacles in the outdoor environment, over stimulation (light and noise) having enough help, and the ability to access help if needed. Consider how much time outside is the appropriate amount of time to optimize the activity. A volunteer or friend may be able to accompany the patient on a short walk or sit with the person outside while they watch nature or people.

Schedules, Routines, Staff Consistency

There is emotional and physical safety in a predictable environment. Creating and maintaining a schedule and a set of routines for activities, meals and snacks, social interaction, and travel routes will promote and maintain comfort and safety in persons living with Alzheimer's disease. Staff is a vital environmental feature. Matching staff with the person living with Alzheimer's disease is important. Staff provides a visual cue for specific activities. If a person with Alzheimer's disease displays a strong reaction

to a staff member it may be related to past events. Be sensitive and adapt to meet the needs of the person living with Alzheimer's disease.

PATIENT RIGHTS AND RESTRAINTS

Patient's rights are a core component of Hospice philosophy of care. Conditions of participation for hospices state that the patient has the:

- right to be treated with dignity and respect.
- right to be able to voice grievances regarding treatment or care.
- right not to be subjected to discrimination or reprisal for exercising his or her rights.
- Patient's rights in relation to restraints, follow these standards.

When Restraints Are Not Justified

The patient has the right to be free from seclusion and any physical or chemical restraint not used to treat a medical condition or in any form imposed as a means of:

- Coercion
- Discipline
- Convenience
- Retaliation

What Is A Restraint?

A restraint is any method that restricts a patient's freedom of movement in order to manage the patient's behavior.

When Restraints Are Justified

Restraints should only be used...

- with due caution and consideration
- when other methods have failed
- when clinically justified to protect the patient and others from injury or harm
- when the patient's behavior disrupts the environment to the point where care and treatment cannot occur

Physical Restraints:

- manual method
- physical or mechanical device
- material
- equipment

Chemical Restraints are:

- drugs used to manage a patient's behavior and restrict movement.

Physical restraints are NOT:

- orthopedically prescribed devices
- surgical dressings or bandages
- protective helmets

- methods that involve holding a patient for the purpose of conducting routine physical examinations or tests or to protect the patient

Chemical restraints are NOT:

- medications used as standard treatment for patient's
- medical or psychiatric condition
- Know which restraints are approved by your agency and how to correctly apply them!

Types of Physical Restraints

- soft limb
- mitts
- lap buddy
- net or perimeter med
- physical/manual method
- soft jacket or vest restraint
- geri-chair with tray
- side rail
- secure limb wrist/ankle restraints

Physical and Chemical Restraints

A restraint is any method that restricts a patient's freedom of movement in order to manage the patient's behavior.

- manual method
- physical or mechanical device
- material
- equipment

Types of Chemical Restraints

The following medications could be considered chemical restraints based on the purpose of administering the medication to the patient.

- Lorazepam (Ativan)
- Haloperidol (Haldol)
- Idazepam (Versed)
- Propofol (Diprivan)
- Chlorpromazine (Thorazine)
- Phenobarbital (Phenobarbital)
- Ketamine (Ketamine HCL)

Opioids may be listed in some articles as a possible agent for sedation, but opioids should only be used for pain. The sedation is a side effect of the medication and not the primary, intended effect of the drug.

ALTERNATIVE METHODS

Review each of the following methods to learn more about interventions that can and should be tried before considering the use of restraints.

Assessment and care of physical issues

Physical issues such as pain, discomfort, full bladder, constipation, some medications, excessive caffeine or sugar, hunger or thirst can cause restlessness, confusion, agitation and other behavioral issues.

Comprehensive assessment and interventions such as pain management, repositioning to relieve discomfort, a bowel regime and frequent toileting, medication review and nutritional snacks are implemented to relieve physical symptoms and help prevent the use of restraints.

Assessment and care of psychological/emotional issues

Assessment and care of psychological and emotional issues is important to help relieve distressing symptoms that could cause anxiety and other behavioral issues or exacerbate pre-existing psychiatric illnesses.

To help relieve psychological pain and suffering, try to determine the underlying cause of behaviors. If appropriate, ask the patient what it is that they want, what they think would help relieve their distress and how you can help.

Changes in the environment

Excessive noise from visitors, other patients or an overhead paging system, a disruptive roommate, clutter, poor lighting, out of reach personal items and other environmental factors can cause or contribute to a patient's fear, anxiety, orientation and general well-being.

Modifying the environment by decreasing noise levels, providing adequate lighting, changing roommates, placing the call bell and personal items in reach and removing clutter may help prevent restlessness, agitation and other behavioral issues. Moving a patient closer to the nurse's station or another room where it is easier for the care team to observe them is also a useful method of changing the patient's environment to meet the need for safety.

Companionship

Companionship can be provided by family members, friends, volunteers, sitters and staff. This may require that visiting hours become or remain flexible.

Volunteers

In hospice, volunteers are a tremendous help and alternative to the use of restraints or seclusion. Hospice volunteers can provide companionship, diversion, and assisted activities such as wheelchair walks, comfort touch, reassurance and presence. The array of volunteer services can help improve a patient's physical, emotional and spiritual well-being and prevent patient issues and situations that could require the use of restraints.

Presence

Presence is a sacred space between two people that can be created by being inclusive, non-judgmental and fully focusing on the patient at that moment in time. Presence does not require that you talk, or problem-solve, or fix anything you perceive as a problem. Presence is actively listening to the patient, fully accepting who that patient is, being compassionate and simply "being with" the patient.

Spiritual care/chaplain visits

Many patients can find comfort and peace through spiritual care.

Visits by hospice chaplains or the patient's own clergy, prayer and participation in religious rituals and sacraments can help prevent or ease fear, restlessness and other symptoms that can cause behavioral issues.

Sitters

Rather than restricting a patient with restraints or seclusion, the family should be given the option to hire a private sitter to assist and watch the patient. Sitters can provide companionship, diversion and assist the patient with participation in activities.

Palliative arts/complementary therapies

Palliative arts/complementary therapies such as aromatherapy, music therapy, reiki, art therapy, massage therapy and comfort touch are alternative methods to help decrease patient restlessness, anxiety, boredom and other symptoms and behaviors that could result in the need for restraints.

Reality orientation

Reality orientation includes frequently orienting the patient to time and place, explaining and repeating explanations of procedures and instructions. Providing items such as clocks, televisions, radios, and familiar items from their home (a favorite blanket or bedspread, pictures of their loved ones) can help keep the patient oriented. Maintaining a daily routine and providing the patient with meaningful activities during daylight hours may help prevent or reduce excessive napping that can result in restlessness, wakefulness and confusion at night.

Diversion

Diversion can help a patient focus on something other than those factors that contribute to behavioral issues. Diversion can be accomplished through television, radio, participation in activities or exercise, hobbies and visits from family and friends.

Exercise

Exercise can help reduce restlessness and includes active or passive range of motion, ambulating from the chair to the bed, sitting in a chair, repositioning and assisted ambulation. Exercise can also help the patient sleep better at night and help relieve stiff joints, muscles and other discomforts that can cause restlessness.

Alarms

Alarm systems can be used on beds and chairs or attached to a patient to monitor the patient, but not restrict the patient's movement. Chair and bed alarms look like simple chair pads. When the patient attempts to get out of the bed or chair unassisted, the decrease of their weight on the pad sets off an alarm which can remind the patient to wait for help and alert staff to the patient's need for assistance. Alarms with a pull cord that is attached to the patient are also helpful. When the patient tries to get out of the chair or bed unassisted, the cord on the alarm pulls out of its socket and sets off the alarm.

Lower beds

If the bed is electric, keep it at its lowest position so that it is easier and safer for the patient to get in and out of bed without hurting themselves.

CARING FOR THE CAREGIVER

According to data from the Alzheimer's Association in 2015, unpaid caregivers provided billions of hours of informal, unpaid care, a contribution worth over 244 billion dollars. This unpaid care to another adult with Alzheimer's disease and other dementia disease is sure to grow in coming years. But despite the huge number of caregivers, they often labor in isolation with little support from their communities, friends or families. More than half of Alzheimer's patients are cared for at home, and 38% of caregivers are women (wives, daughters, daughters-in-law, sisters, other caregivers), 34% were aged 65 years or older. 25% of caregivers may also be raising children, have a job outside the home, be involved in activities outside the home, and play other roles within the family system. Caregivers of dementia patients who are finally facing the end of life are often exhausted in all areas of their life.

Although each dementia experience is unique, those affected will eventually be dependent on others for care in all aspects of their daily life. A study commissioned by MetLife insurance, found that those who were caring for family members with dementia diseases provided more hours of care, experienced greater stress and were more likely to indicate that caregiving had impacted their health than other caregivers. Spouses of caregivers were more likely to have had to quit a job because of caregiving responsibilities. Individuals caring for a family member with Alzheimer's disease or another dementia were 41% more likely to report that caregiving had caused their health to worsen than those caring for a family member with a physically disabling condition.

These caregivers are physically and emotionally challenged by the physical and mental changes and deterioration in the patient that occur over time as well as the care needs. Because Alzheimer's disease is a long-term and life limiting illness, caregivers are at risk for depression, stress, illness, burn-out. They may have difficulty finding any meaning or purpose in the daily toil of providing care to someone who barely recognizes them. Normal emotional responses include resentment, loss and grief, guilt, denial, worry and anxiety. They may feel anger over not being able to stop or control the disease or frustration over communication difficulties with the patient. As the patient experiences losses, the caregiver also experiences losses. Watching the patient become more forgetful, even eventually forgetting who his/her loved ones are, can trigger sadness and grief.

As the patient becomes more dependent and requires more care, the caregiver often must give up outside activities or employment in order to care for the patient. This loss of social, emotional and financial support complicates the tremendous daily care needs of a person with Alzheimer's disease or other dementia disease. Some caregivers may have been providing primary care for many years. They may have limited interaction or activity outside their home. Their loved one is often totally dependent on them for all their care needs. The caregiver's role has been to provide constant care for an extended period. The stress and isolation in these circumstances may make it very difficult for the caregiver to transition to accepting help from others.

For caregivers of Alzheimer's disease and other dementia patients, support from the interdisciplinary group is crucial. Support can and should be provided in a variety of ways to meet the physical, emotional and spiritual needs of the caregiver as well as the patient. Some ways in which the interdisciplinary group can provide support include active listening, presence, normalizing and validating their feelings, assisting with care, providing or assisting the patient and caregiver in accessing resources, respite for the

caregiver, providing support groups or referral to support groups, and affirmation of their changing roles and role as caregiver. Hospice care can be invaluable in making the experience of caregiving positive and rewarding.

One of the hardest things for caregivers to do is care for themselves. Physical, emotional, social and spiritual self-care is important in order for the caregiver to be able to maintain their own health and care for others. To pursue any of these activities, the caregiver may need help recognizing their limits, learning to ask for help, and recognizing emotional responses and feelings associated with providing care to someone with a long-term and life limiting illness. The interdisciplinary team should also help the caregiver recognize the need for self-care and encourage physical activity, proper nutrition, outside relationships, pursuing or developing other interests outside of the care giving role, and spiritual care in accordance with the caregiver's belief systems.

In hospice and palliative care, we consider the patient and family as the unit of care. From the time a person is diagnosed with Alzheimer's disease or another dementia until his/her death, the caregiver will be affected by physical, psychological, social and spiritual issues. Caring for someone with dementia exacts an enormous toll – whether by emotional stress, hours of unpaid care, and risks to the caregiver's own health or disruptions to work, life and relationships. Alzheimer's disease can turn a family's life upside down as it is the family who usually bear the brunt of care.

Changes in Relationships

Changes in roles within the family can affect relationships. With disease progression, the family member/caregiver may need to take on what was once the patient's role and learn new skills to adapt to these roles. For example, the patient may have been the major decision maker, the cook, or the family bookkeeper. The caregiver may now need to learn to cook and learn how to balance the checkbook. Volunteers can often help caregivers learn new skills.

The caregiver might also experience changes in relationships with friends. Caregivers are often so busy caring for the patient that they lose touch with family and friends. The caregiver may feel alone and isolated.

Perhaps the most difficult of changes in relationships are those intimate and personal relationships the caregiver may have shared with the patient. When the patient experiences mood swings, changes in personality or inability to recognize or verbally communicate, the caregiver may experience loss of companionship and closeness. A person with Alzheimer's disease and other dementia disorders can suffer from delusions and hallucinations that can make them suspicious that their partner is unfaithful or that their son is stealing or that their daughter is poisoning their food. These beliefs are very distressing to the people who care for the Alzheimer's disease patient. The patient and caregiver are often no longer able to share important memories and events that occurred or are occurring in their lives. The value and meaning that relationships bring to our lives are primarily based on shared memories. The caregiver may feel as though they have lost the person they once knew, and the future they had planned with the loved one.

Encouraging the caregiver to share their feelings with a psychosocial professional, friends, and spiritual care provider or in a support group may help them feel as though they are not alone. Support and guidance from counseling professionals can help a caregiver find value in their everyday experiences with the Alzheimer's disease patient and meaning in their service of care. Accessing respite care and

taking part in activities with family and friends can help the caregiver continue important and supportive relationships.

Physical Stress of Being a Caregiver

As Alzheimer's disease progresses, the patient becomes more dependent on the caregiver for bathing, grooming, toileting, and feeding. The patient may wander and may even get lost within his/her home. The patient eventually requires 24-hour care and monitoring which imposes great physical demand on the caregiver. Encouraging the

caregiver to ask for and accept help and respite from family, friends, volunteers, outside resources, and through hospice services can help the caregiver better cope with the physical demands of caring a patient with dementia disease.

Emotional Stress of Being a Caregiver

In addition to the physical demands of caregiving, two-third of caregivers of people with dementia disease advocate for their care recipient with healthcare service providers and government agencies. Caring for a person with dementia also means managing symptoms that family caregivers of people with other disease may not face, such as neuropsychiatric symptoms and severe behavioral problems. (2016 Alzheimer's disease Facts and Figures) Emotional stress related to caregiving can occur not only because of the immense responsibility of caring for someone 24 hours a day, 7 days a week, but also because that patient may be experiencing mood swings, undesirable or inappropriate behavior and personality changes. It is not easy caring for someone who is angry one minute, happy the next, and striking out the next. The caregiver may also have a fear of the patient wandering, getting lost, and getting hurt which can cause further emotional stress. Signs that a caregiver may be experiencing emotional stress may include feelings of sadness, anger, guilt, grief, or being overwhelmed.

Letting caregivers know that these feelings are normal may help alleviate some of the stress. Many caregivers have difficulty finding the time to take part in enjoyable or stress-relieving activities as well as support groups.

Encouraging the caregiver to ask for help and encouraging these activities may be helpful.

Financial Issues

Remember that much of the financial burden of caring for a patient with Alzheimer's disease falls on the patient and family. If a family member must also give up outside work to care for the patient, the concern and stress over financial issues increases. The psychosocial professional may be able to help the caregiver tap community and other resources to help with financial burdens.

Spiritual Issues

At the time of diagnosis until the patient's death, the patient as well as the caregiver may be affected by spiritual issues. With a diagnosis of Alzheimer's disease, a patient may question why this is happening to him/her, the meaning of suffering, and the purpose of his/her life. There may be questions of faith as well as issues of guilt and forgiveness. Spiritual issues can be complex and the patient and caregiver's chaplain or other spiritual care provider may be able to assist the patient and family in exploring their feelings towards finding comfort and peace.

Caregiver/ Family Issues and Opportunities

Remember that families, however defined, are complex. They bring their histories, personalities, abilities, skills, strengths and weakness to the care giving experience. These “dynamics” can be a great source of support or may create social, emotional, and functional challenges. It is important to be sensitive to the unique aspects of all caregivers and their families. In this we can better identify areas to educate, support, validate and encourage caregivers and their families.

Family issues in the early stages involves a lot of new worries, anxieties, and adjustments as they learn more about Alzheimer’s and related dementia diseases. At this stage, family members and caregivers may be more alert to safety issues, finances, and a loss of their own free time as they make changes in the home. The patient, who is also adapting to these changes while also dealing with early-stage symptoms, may feel privacy is being invaded. As the patient and family adjust to a “new normal”, issues of independence may arise as the patient begins to rely on family for tasks that were previously done independently.

In the middle stages, previous family issues can become more intensely felt as newer issues arise. As symptoms progress for the patient, healthcare decisions – if not discussed in the early stages – can be a question and main point of contention when family members disagree. The caregiver may feel like they are under increased pressure as more of their time is devoted to caretaking. Managing additional demands around the home can exacerbate mental and physical health problems in the caregiver, making self-care and respite an important aspect of this stage. Issue of independence for the patient may become more apparent as daily life requires more help, and their dignity may be affected by these changes. Advance care planning and conversations surrounding medical decisions can also cause issues for family and patient alike. The health and wellbeing of both the patient and caregiver during this stage is important.

During the late stages, communication is severely affected. Caregivers learn to read facial expressions, body language, and other signs to indicate mood, and patients may use physical gestures as their ability to articulate their needs clearly becomes more difficult. Helping caregivers and family determine these signs can alleviate some stress.

Independence and privacy become additionally difficult as meals, bathing, grooming, toileting, and daily care overall are almost completely steered by the caregivers, both familial and professional. For family caregivers, their careers, hobbies, and social activities may be eclipsed by the need to care for their loved one. Issues surrounding placement in skilled nursing or residential care may be a tense topic among family, and though familial caregivers are under great pressure, giving up full-time care may also cause feeling of loss, resignation, depression, and grief.

At the end of life, the demands of caregiving are great and they can often feel like they are on constant duty or always “on call”. The stresses of caregiving at this stage can be According to the 2019 Alzheimer’s Facts and Figures, published by Alzheimer’s Association, a study found that 72% of family caregivers found relief when the patient died. Conversations surrounding hospice and end-of-life decisions can be stressors for the family, and different opinions may cause additional strain, even when advance care plans were made in the earlier stages.

STAGES OF CAREGIVER ADAPTATION

Early Stage

This is a good time to attend to the completion of worldly affairs (financial, legal, advance directives). Anxiety regarding the future may emerge.

Middle Stage

Caregiver begins to adapt behavior and schedules to accommodate growing physical care, safety, and mobility needs. Home care/ respite services may be appropriate.

Placement in a care facility may be considered at this time. Feelings of guilt may emerge; emotional and physical health may suffer.

Late Stage

Struggles may emerge regarding social, emotional, and spiritual issues. The experience of grief is often present. Increased support is often required.

THE DYING PROCESS

Alzheimer's disease is a terminal illness. As such, it is important to educate and prepare family members about the dying process. Even with severe cognitive impairment, patients with Alzheimer's disease experience that same signs and symptoms of the dying process as other patients. Issues of near-death awareness and physical, emotional and spiritual pain and suffering are the same as with other patients and should be provided the same care and attention.

Because Alzheimer's disease is a long term, chronic illness, caregivers of Alzheimer's disease patients have spent many years providing care. During the final stages of Alzheimer's disease, hospice care is especially beneficial to the patient and their caregivers. The comprehensive palliative care and broad range of services provides support in respecting end of life wishes. The caregiver may need help and reassurance in supporting the patient's living will choices including the individual's right to withdraw or refuse treatment. Withholding treatment for infections, heart failure, dehydration etc. is not the same as assisted suicide or euthanasia, but for the caregiver navigating these decisions is difficult and emotionally distressing.

After the death, the caregiver may feel guilty for wishing the patient would die and/or relief that they no longer have to provide care. Some caregivers may not know what to do as their life for so many years has revolved solely around the care of the patient. Even though these caregivers have dealt with loss for many years and have experienced anticipatory grief, they will still feel grief and loss following the death and should be given the opportunity for bereavement care. Also keep in mind that professional caregivers, especially in assisted living and long-term care facilities may have cared for these patients for many years and will also feel grief and loss.

ETHICAL PRINCIPLES

All persons deserve to be treated with dignity and respect. There several ethical principles that will help to guide these relationships. These include the following.

Autonomy - Persons living with AD and their families have the right to make decisions and act according to their values and beliefs.

Beneficence - Persons living with AD and their families should always be cared for in a manner that promotes wellbeing.

Justice - Persons living with AD deserve access to equal and fair treatment.

Confidentiality - The ethical principle of confidentiality safeguards the privacy of the patient, their family members, and the experience of their illness, dying, death and bereavement.

Veracity - Veracity, simply stated, is truth-telling. It implies not lying, withholding information or deceiving others.

Non-maleficence - Based on the principle of doing good while avoiding harm.

CASE STUDY - MRS. CASEY

Mrs. Casey has advanced Alzheimer's disease. She is still walking. Most of her speech is difficult to understand, but occasionally she responds appropriately. Recently, she has begun pushing food away and is losing weight.

Her doctor has done tests and believes that there is no reversible physical problem such as an infection, pain or constipation that might be causing this. Mrs. Casey's daughter Beth is her healthcare surrogate and she asks to discuss with you.

What ethical issues should be included in the discussion?

Persons living with ADRD and their families should always be cared for in a manner that promotes wellbeing, and they deserve to be informed about the costs and benefits of all care strategies.

Both beneficence and non-maleficence should be included in this discussion.

CASE STUDY - MR. DAVIS

Mr. Davis is a 65-yr old man who has recently been diagnosed with Alzheimer's Disease. He is slightly forgetful but can still make his own decisions. Mr. Davis lives independently and has a large family, all of whom visit him regularly. The family wants to sell all of Mr. Davis' possessions and place him in an ALF. They are choosing to do this without his knowledge or consent.

What ethical principles need to be applied here?

Autonomy and veracity should be applied in this case. Persons living with ADRD and their families have the right to make decisions and act according to their values and beliefs. Persons living with ADRD and their families must be completely informed about their health status and plan of care in an understandable, timely and truthful manner.

CASE STUDY - MR. DOMINGUEZ

You have provided care for Mr. Dominguez 3 days per week for the past year at his home and are aware of his slowly declining condition. You arrive to give him a bath and find his family in tears. His wife reports that over the past 24 hours, Mr. Dominguez has been very restless and unable to lie still. He has not been able to sleep, and yet has not been able to communicate clearly with his wife and daughter

who have remained awake with him. Mrs. Dominguez states that her husband has been speaking in Tagalog (his first language from the Philippines) and talking about his parents who died many years ago.

Mr. Dominguez's daughter is fearful that he will get out of bed and fall. She asks whether he should be restrained. What ethical principles need to be applied here?

The ethical principles of beneficence, non-maleficence and autonomy need to be applied to this case. Persons living with ADRD and their families should always be cared for in a manner that promotes well-being and deserve to be informed about the costs and benefits of all care strategies. Persons living with ADRD and their families also have the right to make decisions and act according to their values and beliefs.

ELDER ABUSE

It should be noted that patients with Alzheimer's disease and other dementia diseases are at a higher risk of elder abuse due to their cognitive impairment, poor judgment, behavioral symptoms, long-term illness, and long-term dependence on others for care. Caring for someone with a long-term illness can cause extreme stress, depression, isolation, financial difficulties and other difficult emotions.

Signs of Abuse

Signs of abuse can include poor personal care, bruises, wounds, burns, and fractures with poor explanation for the injuries.

Reporting Abuse

If elder abuse is suspected, a thorough assessment should be made and reported to your supervisor so that proper care and proper procedures for reporting in your state can be followed.

For more information on elder abuse, refer to the self-learning module "Domestic Abuse, Elder Abuse and Domestic Violence" which can be accessed in the Learn Center.

Community Resources

Community resources can help offset the financial, emotional and physical cost of caring for a patient with Alzheimer's disease. The interdisciplinary team should educate the patient and family about community resources that might be helpful and assist them in accessing those resources if needed. In addition to the community resources listed below, the healthcare professional should also be aware of resources specific to their community and patient populations.

Day Care Centers

Day care centers can provide structured activities and interaction with others, as well as a short respite for the caregiver.

In-Home Services

Meal services, housekeeping services, companions and volunteers adept at caring for a patient with Alzheimer's disease can be helpful to the patient and caregiver.

Alzheimer's Association

The national and local Alzheimer's Association is an important resource for patients, caregivers and healthcare professionals. The association provides information about care and services and supports research and advocates for people with Alzheimer's disease and their families on a federal, state and local level. The Alzheimer's Association can provide assistance with:

- how the disease progresses and what to expect
- finding emotional support for patients, caregivers and professional staff
- securing help for legal, financial and living-arrangement decisions
- learning about current care and treatment options
- obtaining information about clinical trials of potential treatments
- developing skills to provide quality care
- accessing professional and community services
- reducing stress and managing lifestyle changes for the patient and caregiver

In addition, the Alzheimer's Association provides the following key programs and services:

- Safe Return, a nationwide identification program, requires that the registered individual wear an identification bracelet. If they wander away from home, the caregiver can contact the police and the national Safe Return office, where information about the person is stored and shared nationwide.
- Chapter-sponsored support and education programs for individuals with the disease, family members and caregivers
- National and chapter help lines providing information and emotional support
- Educational brochures and newsletters
- National and regional education conferences and program for health care providers, residential care professionals, and other caregivers
- The Benjamin B. Green-Field National Alzheimer's Library and Resource Center, which has a collection of books, audio tapes, video tapes, CDs, periodicals, a Web-accessible catalog, materials in different languages and research services

American Association of Retired Persons

The AARP is a membership organization dedicated to enhancing the experience of aging through advocacy, information, and services. This organization can be a resource for issues and diseases that affect the elderly. Membership benefits may include educational materials and access to various kinds of insurance.

The Area Agency on Aging

The Area Agency on Aging has an Elder Helpline to obtain information about local resources and referral for home delivered meals, adult day care, respite care, personal care services and other services that might be needed by the patient. They also have the SHINE Program for questions regarding health insurance issues.

Legal Services/Elder Law Attorney

Legal planning may include putting together documents to support the patient's healthcare choices. Legal planning should be done as soon as possible after diagnosis. If the patient has the mental capacity to make his/her choices known, understand and sign legal documents, then they should actively

participate in the process. An elder law attorney can assist the patient and caregiver with Living Wills, wills, trusts, power of attorney, guardianships and other legal matters.

Financial Services

Financial issues can be a source of anxiety for the patient and caregiver as healthcare services can be extremely expensive. Financial assistance and health care benefits to help pay for some of these expenses may be able to be obtained through government sources. Some of these include Social Security Disability, Supplemental Security Income, General Public Assistance, Medicare and Medicaid. Social workers have a good knowledge of available resources and can help the family access available financial assistance to meet healthcare expenses.

Faith-Based Organizations

The patient's and family's faith-based affiliations can be a helpful resource. Churches, synagogues and mosques often have nurses, volunteers, and counseling services for their members.

Ombudsman

Patients affected by Alzheimer's disease and other dementia disorders in the later stages of the disease may require placement in a long-term care or assisted living facility. An ombudsman investigates complaints regarding assisted living and long-term care facilities.

CONCLUSION

Alzheimer's disease and related disorders are complex diseases that cause cognitive impairment and physical, emotional and behavioral changes and symptoms. Providing physical, emotional and spiritual care for these patients and their families can be challenging. Knowledge and skills about these diseases, utilizing resources such as the Alzheimer's Association and seeking the assistance and expertise of the interdisciplinary team can help you meet the challenges and provide dignified, compassionate care to patients and their caregivers.

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