Caring for the Resident With Dementia

Inservice Approved for Six (6) CEUs by the
North Carolina Division of Health Service Regulation (DHSR)

This inservice is produced by Moffitt Healthcare to meet the yearly dementia inservice state requirement for assisted living facilities

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Major sections

Learning objectives

1. Understand the importance of the qualities and characteristics of a good caregiver
2. Recite the prevalence of dementia for specific elderly age groups
3. List 5 causes of dementia and cite most common cause
4. Discuss 3 general signs/symptoms of dementia
5. Discuss ways to enhance caregiving regarding activities of daily living
6. Differentiate between early, middle, and late stage Alzheimer's disease
7. Compare mental functioning between normal adults and those suffering from dementia
8. Identify characteristics of early stage dementia and proper response techniques
9. Identify characteristics of middle stage dementia and proper response techniques
10. Identify characteristics of late stage dementia and proper response techniques
11. List 10 challenging, inappropriate, antisocial, or problem behaviors
12. List 10 responses that will enable more effective caregiving for behavior problems

Table of Contents

Introduction

The adult with normal mental capacity forgets, remembers that he forgot, and often remembers what he forgot. The resident with dementia forgets, forgets that he forgot, and does not remember what he forgot.

What is dementia? *Dementia* in Latin means *irrationality*. It has been described in many ways, such as:

"A progressive brain disease"
"Loss of intellectual functions"
"Decline in mental functions"
"Decrease in cognitive functions"
"Impaired memory, reasoning, and other mental abilities"
"Chronic, progressive loss of brain tissue"
"Reversible and irreversible brain disorder"
"Physical disorder of the brain"
"Progressive loss of brain power"
"Senile dementia"

Dementia is a syndrome resulting from underlying causes. Dementia is not an inevitable fact of life for the aged, nor is it some inevitable consequence of aging. It is a sinister type of brain damage with many contributing causes, of which Alzheimer's disease is the most commonly known.

The oldest segment of the population is also the fastest growing. This represents a tremendous challenge to long-term care facilities, because most people who suffer from dementia represent this age group. Although dementia effects all nationalities and ethnic groups, most dementia in long-term care is seen in white groups, as 85% of residents are of this "race."

Dementia incidence seems to double for each 10 years of life past the age of 60. The percentage of the elderly population with dementia is shown in the following chart:

Age Group	**Percentage with dementia**
65 – 74	5 – 8%
75 – 84	15 – 20%
85 and older	25 – 50%

The purpose of this inservice is designed to help you become a more confident and competent caregiver in the realm of assisting dementia residents. This inservice will give you many of the cognitive (thought, intellectual, "know-how") tools you need to give good care to the residents under your charge.

Caring for those with dementia can be rewarding—and it is definitely challenging. Your intellect, your creativity, your emotions, your commitment—all these will be tested and stretched as you care for what is arguably some of the most difficult residents in the long-term care setting.

Please Note The Following Points About This Inservice:

- Under no circumstances is any portion of this inservice to supersede state rules or regulations, or the advice and orders of the physician.
- The main goal of this inservice is to provide practical, instructional information for caregivers who care for residents with dementia in long-term care facilities. This inservice will help the caregiver provide competent and confident care.
- This inservice concentrates on practical caregiving, rather than on the medical, research, or scientific focus on dementia.
- Our focus is to give you some of the raw materials for good caregiving; however, hands-on experience is the very best teacher.
- The helpful tips, hints, recommendations, reminders, and pointers are generalizations for the most part. Physician's orders must be considered first when rendering resident care.
- In referring to residents in this inservice, the pronoun "she" is generally used, since most long-term care residents are female. Unless otherwise indicated, the related material is appropriate for both male and female residents.

What kind of caregiver are *you*?

As we've mentioned, this inservice can give you the tools you need to give better care to residents with dementia. However, we can't give you everything you need. There are some things you have to bring to the table. Your characteristics—those qualities that define who you are—are not something you can learn in an inservice. They are parts of your inherent and cultivated nature.

You need many attributes to be successful in caring for dementia residents. The characteristics we will briefly highlight in this section are ideal, but very much worth striving for. They are not all that hard to achieve if you keep in mind to treat your residents as you would want to be treated if you were in their place. Let's take a quick look at some of the qualities and characteristics of a good caregiver.

Qualities and Characteristics of a Good Caregiver

Empathy

This is perhaps the most important characteristic of a caregiver. Empathy is related to sympathy, but it goes deeper. *Sympathy* is what you feel when you hear news about, say, flood victims in a foreign country. You feel sorry for the victims and their plight. *Empathy* is genuinely caring for someone. It is the one characteristic by whose leading all other characteristics follow. Without empathy no other characteristic matters.

Cheerfulness

Who wants the care of an assistant who looks the part of doom and gloom all the time? We like to be around people who are cheerful. Attitudes tend to rub off on people. Cheerfulness begets cheerfulness while negative attitudes beget more negativity.

Responsibility

The caregiver position is a responsible one. The aide knows that she is responsible to her residents, employer, coworkers, and to herself.

Consideration

The long-term caregiver should be a considerate person who would not knowingly and needlessly do or say anything that would offend the resident. She will help any resident in need and will not refuse to assist a resident. She does not have to be asked to help.

Courteousness

The caregiver is courteous to her residents and coworkers. She is polite and well-mannered. She is gracious in all her dealings.

Cooperation

The caregiver realizes that she does not stand alone in her job. She is part of a team that includes administration, other assistants, doctors, nurses, housekeeping, dietary, maintenance, and so on. She understands that everyone should work for the good of the resident. She is attentive to the direction of her superiors and does not undermine the authority of any of her coworkers.

Dependability

The caregiver can be counted on to be at work when she is scheduled. She is not often absent from the job. She can be counted on to do her job. Her supervisors and coworkers do not have to wonder whether or not she is taking care of her residents.

Honesty

The caregiver is honest with all her dealings with anyone. If she is dishonest with others outside her occupation, she will be dishonest with those around whom she works.

Patience

Residents are different in many ways. Some residents catch on to teaching easier and some are more eager to learn. Others, because of disease processes or handicaps, need more time and effort to accomplish certain tasks.

Respectfulness

The caregiver understands all of the resident's rights and upholds these rights to the best of her ability, respecting the resident's choices, rights, feelings, etc.

Trustworthiness

The caregiver can be trusted to get the job done. The resident and any of her possessions can safely be left to the care of the trustworthy caregiver.

Self-awareness

The caregiver knows who she is. She doesn't live her life trying to find herself. She knows that giving her best for others, whether at home or at work, is one of the grandest callings of life. This confidence shows itself in the quality of her care.

Willingness to Learn

The caregiver is aware that caring for others is not an exact or static science. Changes in political or economic climates, advances in health care, changes in rules and regulations, and even changes in abilities and habits in both the caregiver and the resident necessitate an ongoing need to keep up both mentally and physically.

Tactfulness

The caregiver knows that tact is the art of getting along with others. The caregiver does not make fun of people, especially the sick and infirmed. In the face of controversy she stands for principles while not carelessly provoking or exacerbating conflict.

Competence

The caregiver is knowledgeable about her job and has shown herself to be proficient with the skills required to do her job. She performs her duties correctly and efficiently.

Commitment to the Job

If the caregiver is out of work, she has a legitimate reason. She knows her coworker's jobs are made more difficult if she is habitually absent or tardy. It bothers her when staff members have to work short-handed, because it impedes resident care.

Punctuality

The caregiver knows what it feels like to work hard and she is more than ready to leave work when her shift is done. She does not like it when her relief is late getting to work, so she strives to be there on time when she has to go to work.

Stories of dementia

Raymond

History

81-year-old male who has been a resident at the Woodleaf Assisted Living facility for almost 2 and a half years. Some of his diagnoses include dementia, diabetes, chronic bronchitis, hypothyroidism, anemia, and a history of congestive heart failure, a heart attack, pneumonia, and gout.

Dementia symptoms

He was recently transferred to their special care unit due to his diagnosis of (and worsening) dementia. He is very forgetful and often misplaces things. His long-term memory seems clear, but he has increasingly poor short-term memory. He needs frequent cueing and reminding. He doesn't appear to be as interested in eating as he once was, but he is maintaining his weight.

Difficult behaviors

Raymond is usually very receptive to care but can at times lash out when a staff member tries to give him personal care. He can also be sexually aggressive. Most of his sexual overtures are vocal. He makes rude suggestions. He is beginning to show signs of sundowning. He wanders at times and has been found in other resident's rooms.

Mae

History

92-year-old female, Mae has been a long term resident at the Country Manor Retirement Villa just over 7 years. On her FL-2 you notice the following diagnoses: Alzheimer's disease, chronic urinary tract infections, high blood pressure, hyperlipidemia, psychoses, and dehydration.

Dementia symptoms

Mae does not appear to recognize any family members. She does not speak much, but when she tries, her speech is mostly unintelligible. She never smiles nor does she show any emotion, except when angry, which can happen without notice. She is chair and bed bound and requires total assistance with all ADLs and must be fed.

Difficult behaviors

Mae is quiet for the most part—as long as she is left alone. She quickly becomes animated when staff attempts to provide personal care. She especially hates bathing, which is done every other day as scheduled, but since she is totally incontinent, requires incontinent care several times a day. During bath time, she strikes out at staff, trying to pinch or hit them. She seems much stronger during these times than she usually is. This makes bathing her very difficult.

Bill

History

67-year-old male just admitted to the special care unit of the Smith-Melton Convalescence Center. He has vascular dementia, high blood pressure, TIAs, two strokes, chronic renal insufficiency, and diet-controlled diabetes.

Dementia symptoms

Bill is independent with all ADLs. He seems not to care about how he looks and needs reminding to shave or comb his hair, but is compliant. He denies having any kind of memory problem and always says “you know what it is” every time a question is asked that he cannot answer. He loves sweets and lately prefers nothing else to eat.

Difficult behaviors

For the most part, Bill is an easy resident to care for. He sometimes becomes agitated when asked questions, especially ones that try to illicit memory defects, such as those questions that are part of the Mini Mental State Exam.

Rita

History

74-year-old Hispanic female. She has been a resident of the Sunset Vista for nearly a year. She has Parkinson's disease, a fractured left hip with repair, insomnia, depression, chronic pain syndrome, COPD, and a history of multiple falls with fractures. She was a 2-3 pack a day smoker until admission to the facility and continues to smoke a couple cigarettes a day with staff supervision.

Dementia symptoms

Rita is a high fall risk, as evidenced from her history. Her memory seems to “come and go” as sometimes she seems fully oriented and other times can be a little confused. Her physical symptoms are more significant. She has remarkable tremors to both hands, more pronounced on the right. She uses a walker for assistance with ambulation, and usually remembers to use it, but is often unsteady anyway. According to physical therapy, she has “maxed out her potential.” She requires pain medication daily; some pain meds are scheduled, some are PRN. Her posture is a bit rigid and her pace is slow. She requires assistance with all ADLs except eating, and has to be reminded.

Difficult behaviors

Rita is not much of a talker, preferring to keep to herself. You note chronic depression and she always appears sad. She will become anxious if she cannot smoke a cigarette when she wants. She will shadow (follow) staff members until they take her outside to the appropriate smoking area. She does not sleep through the nights most of the time; this is when she is more likely to be confused and disoriented.

For each of the above resident scenarios, how would you answer these questions?

1. What level of dementia would you put this resident at? (Early, Middle, or Late)
2. What specific difficult behaviors is this resident showing?
3. What would you do about the difficult behaviors this resident exhibits?

Try to answer these questions now. Then, once you have completed this inservice, come back and answer them again. See how your answers compare.

Dementia—causes, signs, & symptoms

All of us have moments of forgetfulness—we misplace our car keys, can't find our sunglasses, and forget appointments. Many otherwise intelligent people can be quite "absent-minded". This is normal and affects people of all ages. We still know what our car keys are for, how to put on our sunglasses, and remember that we forgot the appointment. Dementia is not about being absent-minded.

The person with dementia will eventually forget how to use car keys, what sunglasses do, and couldn't care less about missing or forgetting appointments. This is because dementia, unlike normal forgetfulness or absent-mindedness, is a result of brain damage that profoundly effects the person's ability to process information.

Dementia in a broad sense is a decline in mental functioning. Dementia, according to Dr Jean Hubble of Ohio State University, is a "Cognitive impairment of sufficient magnitude to hinder daily activities or diminish the quality of the patient's life." The word *cognitive* simply refers to the mind and what it is able to do. Memory, decision making, making moral choices, solving problems, thinking, perception, judging, planning, organizing, and emotions are some cognitive elements.

What causes dementia?

Dementia is caused by a destruction of brain cells (neurons). This destruction itself can be caused by any one of a number of illnesses or conditions. Now it is important to know that although dementia always reflects memory impairment, not all cases of memory impairment is caused by dementia. There are many potential causes of loss of memory or confusion, some of which are temporary and reversible, while others are not.

Primary (progressive, permanent, non-reversible) causes of dementia	**Secondary (potentially reversible, may be permanent) causes of dementia**
Alzheimer's disease	Head injury
Parkinson's disease	Dehydration
Huntington's chorea	Depression
Vascular dementia	Fatigue
Lewy body dementia	Metabolic disorders
Pick's disease	Medication side effects
ALS (Lou Gehrig's disease)	Hypothyroidism
AIDS dementia complex	Malnutrition
Creutzfeldt-Jakob's disease	Infections
Alcoholism (neuron destruction)	Brain tumor

Neurosyphilis dementia	Stroke
	Seizures
	Alcoholism related to vitamin B1 (thiamine) deficiency
	Hypoglycemia
	High calcium levels (hypercalcemia)
	Liver disease

Dementia (also called *senile* dementia) is not the result of normal aging processes. It is caused by destruction of brain cells (neurons). Notable statistics:

- There are primary and secondary causes of dementia—primary causes are progressive and irreversible; secondary causes may be reversed or halted
- More women than men have Alzheimer's, because women live longer, but per given population, Alzheimer's affects both sexes equally
- Alzheimer's disease ranks seventh as the leading cause of death past age 65
- On average, a third of American families will have one parent who suffers from Alzheimer's
- Alzheimer’s disease accounts for 50-75% of all dementia
- 20-30% of dementia is caused by “mini-strokes”
- Death from Alzheimer's disease is 7-10 years from first symptoms

On the next page, take a look at some of the signs and symptoms of dementia.

Signs & symptoms of dementia

(There are 10 areas where you might notice some problems)

Recent Memory Loss

Forgetting things and not remember them later

Long term memory usually good in early stages of the disease

Asking the same question repeatedly

Problems With Language

Forgetting simple words

Using wrong words

Comprehension declines

Poor Judgment

Inappropriate decisions

Leave an important task unfinished

Abandonment

Misplacing things

Often hides things in a similar place

Accusing others of stealing

Items often have little or no intrinsic value

Personality changes

Do things ordinarily would not do

"Not the same person" as personality is wiped away by disease process

Irritable, fearful, suspicious

Difficulty Performing Familiar Tasks

Doing a task part way, then forgetting how to finish it

May do a familiar task over and over (repetition)

Forgetting how to do something familiar

Disorientation

Time and place

Often oriented to person, self

Intermittent at first

Difficulty With Abstract Thinking

Does not recognize symbols

Problems with association

Mistakes fantasy for reality

Mood changes

Usually unpredictable

Behavioral problems increase

Fast mood swings

Loss of initiative

Often becomes passive

Might not want to see familiar people or go places

Depression is common

Major causes of dementia

In this section we'll take a look at five of the most common types of progressive, unrelenting dementia. By far the greatest space is devoted to Alzheimer's, as this is the cause of at least 50% of all dementia—as many as all other causes *combined!*

One of the most important reasons we want to discuss different types and causes of dementia is that your care of the resident in part depends on how the dementia manifests itself.

Some forms of dementia are slow to evolve, while others can progress rapidly. Arming yourself with a little knowledge will help give you a "leg up" on the care you need to provide. The five types of dementia discussed here are:

- Alzheimer's Disease
- Vascular Dementia
- Parkinson's Disease
- Lewy Body Dementia
- Huntington's Chorea

Alzheimer's disease

Alzheimer's disease is by far the most common cause of dementia, so we'll spend the majority of our time in this chapter with this form. So, let's get started. How can you tell if a person has Alzheimer's disease? Well, she...

- does not notice a dangerous situation
- becomes confused or unpredictable under stress
- forgets to turn off appliances or water faucets
- forgets to close doors
- becomes confused or disoriented
- forgets things she once remembered
- forgets how to use a telephone or other familiar objects
- becomes withdrawn, depressed, unhappy, or agitated when left alone

Alzheimer's eventually flattens a resident's former personality. In the table below, compare some personality traits before and after the onset of Alzheimer's.

Personality traits *before* Alzheimer's	**Personality traits *after* Alzheimer's**
Active	Withdrawn
Loving	Uncaring
Calm	Easily upset
Honest	Dishonest, steals
"Goes with the flow"	Rigid and upset with change
Likes new experiences	New experiences upsetting
Friendly	Hostile
Sexually private	Sexual inhibitions
Careful	Careless
Controlled	Emotional
Good judgment	Bad judgment
Not suspicious	Paranoid

Here is a list of 10 questions. The more the "yes" answers, the more likely the person has Alzheimer's disease. (One or two "yes" answers can be the result of chance and does not necessarily indicate Alzheimer's.)

1. Is the person forgetting names or recently learned events or information?
2. Is the person having trouble remembering how to do familiar things?
3. Does the person repeat words or phrases or forget the names of things or objects?
4. Does the person get lost or have trouble getting back to the room?
5. Does the person make wrong, simple decisions, such as dressing for the wrong kind of weather?
6. Is the person having trouble with numbers or sequences when this was not a problem in the past?
7. Is the person leaving things in strange places?
8. Is the person more "moody" than usual?
9. Is there a personality change, such as being more dependent, worried, confused, or suspicious?
10. Is the person becoming passive—watching a lot more TV, sleeping, losing interest in things that once held interest, or doesn't care what others think?

We can divide the progression of Alzheimer's disease into stages. This will help you see how different mental, emotional, and physical components change as the resident declines. Please note that there is no official number of stages, and some experts divide the disease into a dozen or more levels. For the sake of simplicity, we will split Alzheimer's into three stages.

Keep in mind that many of the symptoms overlap and there is no definite line between the various stages of Alzheimer's disease. Also, no two residents will show the same symptoms or the same degree of decline in any one symptom. But, the progression is always toward the negative, a decline in the functioning until that function is completely lost—or until death occurs.

Early Stage Alzheimer's (mild)

You will not see much of a physical manifestation in Alzheimer's disease in the beginning stage. Brain cells are already being destroyed, yet there are no outward signs. Most of the symptoms are related to a decrease in memory.

Although any of us could experience some mild memory loss as part of the normal aging process, an Alzheimer's sufferer will experience more rapid and noticeable changes. Even so, changes are gradual and often not obvious at first, and some of the symptoms might be present for months or years before one decides to seek medical treatment.

The resident with mild dementia is usually able to compensate for the decrease in memory and, barring other medical problems, is normally independent with ADLs. In this early stage, trying to establish or force routines is not necessary. In fact, new experiences most likely contribute to good mental health, as the mind is still capable of processing new information.

Symptoms of early stage Alzheimer's disease include:

Mental

- Memory loss—good long-term memory but has problems with daily events; she may repeat questions, misplace things, or not follow a conversation
- Forgetful—may forget names, make up words, current events, short-term personal events, some portions of their own history
- Poor judgment—makes wrong decisions about what used to be familiar and easy; finds it harder to make correct and logical decisions; defers to others
- Money and math problems—losing ability to reason in a consecutive, logical fashion
- Misplaces things—puts items in strange places; forgets where items are put; hides things
- Trouble concentrating—dislike of challenges; does not take up new things; avoids changes
- Repetition—might repeat a story, phrase, question, or statement in the same conversation
- Denial—the resident may deny she has a problem with the memory, although some residents will tell you that they do have trouble remembering things
- Covering—Alzheimer's sufferers can get quite good at covering up their declining memory (she may say something like, “You know what my name is.”)
- Disorientation—a general decline in her sense of direction; she may not be able to give the correct date; she may not remember appointments
- Trouble with routines—less able to handle finances and may have difficulty with normal routines without reminders
- Strange, idiosyncratic behaviors—hoards, hides, or searches for objects of little value; checks on something frequently

- Apraxia—she may forget how, or find it difficult, to use simple tools or appliances
- Anomia—she might forget the right name or word; “It’s on the tip of my tongue.”

Emotional

- Personality changes—more withdrawn and can be inconsiderate of others, and more easily frustrated, sensitive, or irritable
- Apathy—at least 40% of Alzheimer's victims become apathetic; less emotionally involved; a general lack of interest

Physical

- Diet changes—eats very little, or very much, or perhaps lots of one food
- Decline in grooming—a previously well-groomed person might go longer between baths, not comb her hair, or gets more slack in other personal hygiene

Tips for early stage Alzheimer's

- Focus on one topic at a time
- Follow a routine and offer reminders as needed
- Do the most difficult things in the morning when she is most alert
- Make sure that ADLs are done
- Encourage independence

Middle Stage Alzheimer's (moderate)

In the middle stages of Alzheimer's, previous declines get worse and new ones develop. The resident will have steeper mental declines, more noticeable personality changes, and obvious physical problems. She will also become more dependent on caregivers.

This stage is the longest and can be the most challenging, as there are tremendous mental and emotional changes, and the advent of physical ones as well. The resident does not handle new experiences very well, as they can be upsetting or confusing. Routines become more important. John Bayley, in his book *Elegy for Iris*, says that *“*Routine is a substitute for memory” (p. 271). Some of the specific problems you will see with the resident in this stage of Alzheimer's disease follows:

Mental

- Memory loss—declining short-term memory; for instance, she may not remember she has just eaten; she will forget where some of her things are and may try to steal from others
- Loss of awareness of memory loss—most residents at this stage are not aware that they are losing their memory or are not communicating clearly
- Recognition—the resident can recognize many familiar faces, but has much more difficulty remembering names

- Lack of clear thinking—she is no longer to think in consecutive or logical terms and cannot follow sequential instructions
- Disorientation—she might not remember the name or relationship of a close relative; she might believe the present time is 10-30 years in the past; harder time remembering the season, month, year, day of the week
- Language problems—her speech may be slower; she will probably take more time expressing her thoughts; she'll have difficulty finding the right words to say; she might revert back to her original language, if she speaks more than one; problems with reading, writing, speaking
- Diminished comprehension—the resident might still be able to read, but might not understand what she read or respond correctly to questions about the material
- Disconnection from reality—she is less able to tell fiction on TV from reality and less likely to recognize herself in a mirror
- Delusions and hallucinations—more likely at this stage, suspicious, paranoid
- Sundowning—her confusion increases late evening/night.
- Delusions/hallucinations—she would be more prone to these late in the day or during the night but anytime during the day is possible; many such experiences can be frightening; she might become suspicious, paranoid
- Inappropriate behavior—she might undress in the presence of others; she may make improper comments and exhibit fewer inhibitions
- Idiosyncratic behaviors—increasingly seen, including inappropriate sexual behavior, inappropriate undressing, rummages, hides things, steals, repetitive behaviors

Emotional

- Depression—although common among residents, caregivers are even more likely to be depressed
- Agitation—she is more likely to get angry or anxious if she cannot express her needs or if she is confused; physical and verbal outbursts are more common; she might yell or throw things
- Social withdrawal—she is more likely to be depressed and may withdraw from social activities and events; she will be more dependent on caregivers

Physical

- Fine motor skills problems—she might not be able to tie her shoes; might have trouble using eating utensils
- Wandering—a fourth to a half of Alzheimer's residents wander
- Dietary changes—she may eat erratically, leading to weight gain or loss
- Decreased bodily control—less control of bodily functions, increased incontinence, need for cueing when eating, more assistance with ADLs
- Restlessness—she is more likely to fidget, wander, or pace; she might be unable to sit for long and may wander aimlessly
- Sleep disturbances—she might mix up her day/night cycles; it is not uncommon to sleep 14-16 hours a day; some residents might sleep only a couple of hours at night and take no naps; napping even during a meal is common

- Needing assistance—help will be needed for some portions, perhaps all, of activities of daily living

Tips for middle stage Alzheimer's

- Emotional stimulation, such as touch or music, can often soothe her
- Routines are increasingly important, so structure the day and offer a consistent environment
- Remind or cue about the time of day
- Help them look forward to the highlights of the day (markers)
- Keep the environment familiar, be near the resident
- Set routines around regular toilet visits
- Daily routines should be established, but try some novelty to lessen boredom
- Improve appetite by giving oral care daily; keep environment clean and inviting
- Her comprehension might be better than her ability to speak, so talk to her as she talks to you; in other words, if she speaks in single words, speak back in single words
- Assist with ADLs as needed

Late Stage Alzheimer's (severe)

At this point in the resident's life, the former personality is almost completely dissolved. Mental capacity has remarkably deteriorated. Many brain cells in all areas of the brain have died. This has profound negative affects on all body organ systems.

In the early stages, most problems were mental, especially in terms of the memory, but in the last stages, physical problems are most obvious and take most of the caregiver's time. The “wild swings” and extremes in disruptive behavior are reduced or gone. Both body and mind are rapidly deteriorating and failing. The resident cannot control many bodily functions and requires total care with many ADLs.

Mental

- Memory loss, both short term and long term memory, are extremely impaired
- Likely will not be able to understand what others are saying
- May not recognize anyone
- May not recognize self in a mirror
- Does not speak or mumbles just words or phrases, not complete sentences
- Meaningful communication skills are virtually gone

Emotional

- Does not smile or show pleasurable emotion.
- May cry or moan frequently.
- Emotional reactions are usually not appropriate for the occasion or exaggerated.

Physical

- Simple reflex actions are very noticeable
- Easily startled with loud or sudden noises
- Grabs objects or people and doesn’t let go, as in shaking someone’s hand
- Coordination becomes more difficult
- Increasing trouble walking and will likely become chair/bed bound
- More frail, which increases the chance of infection, muscle atrophy, and general physical decline
- ADLs—eating, toileting, ambulation/mobility, bathing, dressing, grooming, and transferring—must be assisted
- Totally dependent on caregivers
- 24-hour supervision is necessary
- May have trouble eating and may even forget how
- May refuse to eat
- Weight loss is common, despite use of supplements and attempts to get her to eat
- Changing sleep cycle—she may be able to sleep only with the help of medications
- Likely will be unable to speak or speaks “gibberish” or inappropriate words
- Often appears uncomfortable, but may cry out when handled or touched
- No longer responds positively to touch
- Pats or touches things repeatedly
- Cannot control movements
- Potential for seizures
- Fully incontinent
- Rigid muscles
- Bed or chair bound
- No longer wanders, as ambulation is now not possible
- Frequent infections, i.e., UTI, pneumonia, pressure wounds, etc.
- Swallowing difficulty
- Skin becomes more fragile and skin tears are common
- Sleeps more

Vascular dementia

Vascular dementia is the second most common form of dementia, after Alzheimer's disease. It's not really a single disease, but rather a complex of syndromes related to blood flow in the brain. Unlike Alzheimer's, vascular dementia is preventable.

You may know vascular dementia by some of its other forms or names:

- Multi-infarct dementia
- Mild vascular cognitive impairment
- Vascular dementia secondary to stroke
- Vascular dementia secondary to TIAs
- Mixed dementia (combination of vascular dementia and Alzheimer's

The differences in the above types of dementia are related to the cause, presence of concurrent dementias, and manifestation of the dementia.

Vascular dementia is far more likely in residents who have a history of stroke or TIAs (*mini strokes*). Strokes are caused by interrupted blood flow to a specific portion of the brain. Strokes occur when a clot blocks an area of blood flow, or when the reverse happens—blood hemorrhages (leaks) into brain tissue, impairing circulation.

The symptoms and progression for those who suffer from vascular dementia are different than those with Alzheimer's. This can sometimes be seen with the Folstein Mini Mental State Exam, which we'll cover in a moment. First, look at some specific facts about vascular dementia:

- Vascular dementia shows a progressive decline in cognitive ability and loss of memory
- It affects the cortex, which is responsible for learning, language, and memory
- Vascular dementia is more likely in men
- It affects primarily the 60 – 75-year-old age group
- The incidence increases in both sexes with age
- It is the 2nd most common cause of dementia
- MID (multi-infarct dementia) is the most common subtype
- Symptoms similar to dementia in general and can appear gradually or rapidly, especially with a major stroke
- TIAs can cause short duration interruptions in blood or nutrition to the brain, which over time causes problems, because of accumulative damage
- An aneurysm or plaque buildup can impair blood circulation to the brain, making vascular dementia more likely
- HTN is felt to cause about half of vascular dementia cases
- Any risk factor that can increase the likelihood of a stroke can increase the chance for vascular dementia, so lowering the risk of stroke will lower the risk of dementia
- Residents with vascular dementia often show poorer verbal skills and more repetitive behavior (words, phrases, gestures) compared to residents with Alzheimer's

The **Folstein Mini Mental State Exam** is often performed on residents to help determine the level of cognitive impairment. In the Alzheimer's resident, you will notice *global* deficits (some impairment in all categories). With vascular dementia, results will be "patchy" (does well in some categories, poorly in others).

The exam is divided into 5 general areas:

- Orientation
- Registration
- Attention
- Recall
- Language

Orientation

Ask the resident the date, day, year, month, and season. (*Score 1 point for each correct answer, maximum of 5 points*.)

Then ask the resident "place orientation" questions: the name of the facility she is in, her room number, the town she lives in, the state, and the country. (*Score 1 point for each correct answer, maximum of 5 points*.)

Registration

Ask the resident to repeat back to you any three objects you name—objects should be familiar, such as "apple," "table," and "box". (*Note how many attempts it takes her to name all three objects & score 1 point for each object named correctly—max 3 points*.)

Attention

Have the resident to spell the word "world" backwards. (Alternatively, have her count backwards from 100 by 7's, stopping after 5 answers.) (*Score 1 point for each letter or number in the right place—maximum of 5 points*.)

Recall

Have the resident recall the three objects you had her remember from the *Registration* section above. (*Score 1 point for each object remembered—maximum of 3 points*.)

Language

1. Ask the resident to identify a pencil and a watch, as you point to each. (*Score 1 point for each correct answer—maximum of 2 points*.)
2. Ask the resident to repeat this phrase: "No ifs, ands, or buts." (*Score 1 point if successful*)

3. Ask the resident to follow a 3 step command. (This is the one I use: “Take this sheet of paper, fold it in half, and drop it on the floor.” *Score 1 point for each step done as you specify—maximum of 3 points*.)
4. Write this phrase on a sheet of paper: “Close Your Eyes” and show this to the resident, asking her to “Read this and do what it says.” (*Score 1 point if done correctly*.)
5. Ask the resident to write one short sentence. (*Score 1 point if she can write a coherent, reasonable sentence, even if shaky or a little sloppy*.)
6. Ask the resident to copy two intersecting pentagons. (Pentagons are 5-sided, closed diagrams—similar to a square but with 5 sides instead of 4—and they should intersect at two points—*Score 1 point if drawn reasonably as you present them, intersecting in two points*.)

The resident can score a maximum of 30 points if she does everything correctly. Though a score below 24 is suspect for dementia, take into account her level of education and any sensory impairment that could affect the score, such as blindness or hearing loss. This test is done to give an objective frame of reference as to how her mental faculties are working, so sensory impairments could give a false low total score.

Test results can be affected by the time of day, so be consistent to perform this test at the same time of the day when testing the same resident. To get a sense where the resident is trending over time, perform subsequent tests every so often, such as every 6 months to a year.

Parkinson's Disease

Parkinson's disease is a progressive disease of the central nervous system, affecting more than 1.5 million people in the United States. It is a type of movement disorder, whose manifestations are most pronounced in the physical realm. Most notable are the rigid muscles, slowing gait, and speech and swallowing problems that characterize many Parkinson's residents.

Parkinson's disease can also cause dementia, but only about 20% of these residents develop it. When it does, it is usually seen in the later stages of the disease. Around ¾ of Parkinson's residents with dementia have the Alzheimer's type. Please note the following about Parkinson's:

- The “Parkinsonian gait” is commonly seen and noted as shuffling, bend forward or backward, hunched shoulders, very little if any arm movement or swing; “freezing” or stopping in the middle of a stride is common
- Parkinson's is characterized by rigidity and tremor, posture and gait problems
- Motor skill problems are the most common issues with Parkinson's; much of your care is steered to this area
- These residents often lack energy, and pain is a frequent complaint
- Tremors are seen usually when resting and can involve the hands, forearms, feet, chin, fingers, or mouth
- About 20% of Parkinson's residents will suffer from dementia, and are at higher risk if they have hallucinations or severe motor skills problems
- Dementia related to Parkinson's usually develops after age 70, about 10-15 years after onset of Parkinson's in most people

- In Parkinsonian dementia, memory problems, slower thinking, moodiness, confusion, disorientation, lack of motivation, and being easily distracted are seen
- Dementia not caused by Parkinson's would more likely show up as delusions, language problems, agitation, and early onset of symptoms
- Feeding techniques for those who have difficulty swallowing will need to be incorporated
- Safety in the environment is a prime concern, as motor skills are affected and falls are common
- Assist as needed with ADLs including ambulation and transferring

Lewy Body Dementia

Lewy body dementia is named for the presence of *Lewy bodies* in the brain, protein deposits that build up and destroy neurons, or brain cells. Whereas Alzheimer's destroys massive amounts of brain tissue, Lewy bodies kill maybe 10-15% of neurons, but can impair surviving ones. Even so, Lewy body dementia takes on characteristics of both Alzheimer's and Parkinson's.

Dementia associated with this disease primarily affects:

- Language
- Memory
- Reasoning ability
- Judging distances
- Carrying out simple actions

The three main symptoms associated with Lewy body dementia are: recurrent visual hallucinations, fluctuating confusion or alertness not related to sundowning, and physical Parkinson's symptoms. If any two of these are present, there is a high degree of probability of Lewy body dementia.

As for commonality, Lewy body dementia accounts for roughly 15-20% of all forms of dementia. Complicating diagnosis and treatment, it can occur alone or in conjunction with Parkinson's or Alzheimer's diseases. It usually has a more rapid progression than Alzheimer's dementia. It is twice as common in men. No causative factor is known.

- Lewy body dementia can show a strong psychotic feature, such as recurrent visual hallucinations, up to 80%, which usually happen at night and involve people or animals
- Delusions are common
- Residents often "act out" dreams
- Falls are frequent
- Hypotension (low blood pressure) is common, so watch for this, especially when getting up from a sitting or lying position
- Fluctuations in autonomic nervous system processes can be seen, which show up as changes in vital signs, swallowing, and elimination swings
- Symptoms can vary from day to day

- Residents with Lewy body dementia can have a poor response (or be extremely sensitive) to antipsychotic meds
- Observe how meds affect the resident, especially if the resident has Parkinson's disease, as meds for hallucinations, delusions, and behavioral problems can worsen Parkinson's symptoms, while meds for Parkinson's can worsen the Lewy body symptoms
- Like other forms of primary, progressive dementia, the exact cause is not known nor is there a cure; treatments are primarily directed at the symptoms

Huntington's Disease

Unlike the other dementias we have looked at, Huntington's disease is a purely genetically controlled disease. It is *autosomal dominant*, meaning that one could feasibly inherit the disease from only one parent (roughly, a 50/50 chance of getting the disease if either parent has it).

Around 30,000 people in the United States have Huntington's, which, in the later stages, shows *chorea*, the uncontrollable, jerky, random movements that are a hallmark of the disease. This begins as an unsteady gait or slow movement, but progresses as the disease advances. The face loses expression. Eventually, swallowing, eating, speaking, and mobility are severely affected and much personal care is needed.

Other physical symptoms can include moodiness, lack of coordination, tics in the face, feet, fingers, and truck, grinding teeth or clinching the jaw, and balance difficulty.

Mentally, symptoms depend on the exact affected areas of the brain. Memory is usually not affected, but the ability to remember new skills is. Perceptual skills and abstract thinking is affected. Poor judgment is common.

Psychological effects are every bit as apparent and sometimes more difficult to deal with than the physical or mental ones. Part of the reason for this is that the symptoms tend to vary more. Depression is very common (as memory is retained, they know what they are going through) and suicide is much higher than average. Aggressive behavior, addictions, inability to recognize disgust in others toward certain tastes or smells, anxiety, and compulsiveness are commonly noted. Here are some notes about Huntington's disease to keep in mind:

- Huntington's disease is an inherited mutation that damages the basal ganglia; it's a genetically controlled accumulation of protein to the part of the brain that controls the person's ability to talk, move, and think
- Onset of symptoms can occur in childhood but usually at 35-50 or later
- Good nutrition, exercise, psychological and spiritual support are major needs of sufferers of this disease
- Speech therapy can help improve speaking or swallowing difficulties
- Thickener agents can be added to liquids
- Nutrition becomes even more important; they need 2-3 times the normal calorie intake
- As with other primary dementia, Huntington's cannot be cured but the disease can be countered with good caregiving and relief of symptoms, helping the resident to enjoy a fuller, more satisfying life

Treatments for dementia

Treatments are geared toward relieving or reversing the dementia (if possible) and combating related behavioral problems. Treatment for dementia has numerous modalities, depending on:

- Cause
- Degree of dementia
- Presence of behavioral problems
- Presence of other chronic or acute conditions
- Wishes of the resident and family

If dementia is progressive (or there's no hope of recovery) the goal of treatment is to control the symptoms and make life for the resident as comfortable and pleasant as possible. There are two broad, important ways to intervene for someone with dementia:

- **Pharmacological** (medications)
- **Non-pharmacological** (not related to meds)

Let's look at these a little more closely.

Pharmacological

Unfortunately, no drug prevents or cures dementia. But there are meds that can help relieve some of the symptoms and even help memory for a while.

Some of the more common medications given to dementia residents include:

- Aricept, Reminyl, and Exelon—these can help restore cognitive functioning to where it was maybe 6 – 9 months ago (or can slow memory loss somewhat); but they do not prolong life or stop the progression of dementia-related symptoms
- Aricept—modest benefits, but does not alter or prevent disease course
- Namenda—for moderate to severe Alzheimer's dementia, can show behavioral and cognitive improvements
- Exelon—can be helpful for residents with fast progressing dementia, even in later stages of the disease
- Melatonin—natural hormone that helps with sleeping; often deficient in residents with dementia
- And, of course, there's a whole litany of antipsychotic, antianxiety, antidepressant, anti-inflammatory, pain management, and other types of meds for dementia-related issues and concurrent conditions
- Nausea and diarrhea are common side effects of dementia meds

Be sure to note and follow the reminders given below:

- Give meds as ordered; do not forget doses
- Document all refusals and notify MD if this happens frequently
- Observe for side effects of dementia medications—read up a little on how these drugs work and what some of the possible side effects are
- Report any suspected adverse reaction or worsening behavioral problem after beginning a new medication, especially antipsychotics
- AIMS (Abnormal Involuntary Movement Scale) should be done periodically for residents receiving antipsychotics (every 6 months)—assesses for abnormal movements that could be a side effect from taking this class of medications

Non-Pharmacological

There are many non-medication ways of treating dementia, with varying degrees of success that depends on a wide range of factors. Hospitalization, surgery, nutritional support, controlling blood sugar, activities—all are ways to treat dementia. Of course, medications are usually used in conjunction with any of the above. Here are some specific, non-pharmacological ways to treat dementia:

Treatment
Prevention
Environmental modifications
Education
Activities

- *Treatment* of the underlying disease—dementia from head/brain trauma, nutritional deficiencies, infections, hormone or metabolic disorders, drug overdoses, and tumors might be reversible to some degree
- *Prevention*—the goal of any treatment is not only to improve present symptoms, but also to prevent, if possible, the occurrence of new ones
- *Environmental modifications*—long-term care facilities will already have met general compliance—always strive to maintain a safe environment that minimizes the risk of falls and is conducive to general well-being
- *Education*—staff should be properly motivated and trained on how to manage behavioral challenges—that's what this inservice is about! (Families, too, should be educated about their loved one's condition and expectations for the future)
- *Activities*—one of the most important ways to improve quality of life and control behaviors—some ideas about activities in general:
  - Encourage physical activity (added benefit is that it helps with sleeping).
  - Activities should be based on something the resident is willing to do and can do, but should be somewhat of a challenge.
  - Activities should not be something that the resident feels isn't useful.

- Activities should be adult level, gender oriented, and familiar.
- Do simple activities that use current abilities.
- Show the resident how the activity is done—cue or demonstrate.
- While stimulation is important, keep within her ability to prevent frustration.
- Break activity into smaller steps or component parts.
- Praise is important for accomplishments.
- Watch for frustration and redirect as necessary.
- Note any discomfort or over-exertion.
- Scheduled activities should generally be done daily at the same time.
- Therapies can involve music, art, pets, storytelling, aroma therapy, psychotherapy.
- Build activities on established memories and activities—don't try to reinvent the wheel.
- Keep activities down to a half hour or less, as dementia residents have less attention span.
- Don't push; watch for frustration.

Dementia & activities of daily living (ADLs)

During the earliest stage of dementia, the resident is likely independent with her activities of daily living (ADLs). As dementia increases, so does the need for assistance with personal care. Although the exact nature and expression of dementia varies from one resident to another, the degree of assistance required is mostly dependent on how far the disease has progressed. The later the stage of dementia the more care will be required. No matter what causes the dementia, its progressive nature will cause declines in the resident's body, mind, and emotional state.

Before you assist with any activity of daily living, let the resident know what you plan on doing and how she can help. You are then less likely to surprise or upset her. She will be more likely to cooperate. Be aware that the resident may buck your attempts to help with her personal care, at least partly because the need for assistance admits loss of independence and privacy.

In this section we'll look at seven of the most basic and important ADLs you will assist the resident with. These ADLs are:

Eating
Toileting
Ambulation
Bathing
Dressing
Grooming
Transferring

Now, let's look at dementia care with ADLs in more detail:

Eating

Eating is one of the greatest pleasures of life. The resident with dementia, even from the earliest stages, may show some problems with diet. Though she can feed herself in those early stages, she may not eat nutritiously, she may eat the same foods continuously, or begin eating less or more than usual.

Advancing dementia is, of course, not the only thing that can interfere with the resident's eating habits. These should be addressed in addition to the dementia. Some other possible causes of poor eating habits include:

- Infection
- Brain damage not related to dementia
- Poor oral care/hygiene
- Missing teeth/dentures
- Mouth pain or discomfort
- Medication side effects
- Not feeling hungry
- Pain

- Visual changes
- Chronic illness
- Psychological factors, such as too much noise, change in routines, being bored, depression, feeling rushed, responding to the moods of others

Some tips that will help you encourage adequate intake and more pleasurable dining experience would include:

- Give good oral care so taste buds can be more sensitive to taste and so food in general tastes and smells better
- Make for a pleasant eating environment—control unpleasant odors, get rid of unpleasant looking objects, minimize noise, and make the dining area brightly lit
- Do not use plastic utensils; they can be broken if the resident bites down too hard
- Wash the resident's hands (or cue them to do it) before eating
- Don't use table settings with patterns (table cloths, plates, napkins, place mats); keep it simple
- More frequent, smaller meals might work for those who eat poorly or eat constantly
- Be sure to offer enough liquids, as older people produce less saliva
- The resident should have regular dental visits as needed
- Try feeding most of one food at a time and avoid mixing foods, as the sudden or frequent change in the taste and textures of different foods can be confusing
- Use straws or cups with lids to make drinking easier
- Prepare food as needed: cut meats, open beverage containers, place silverware on the side of the resident's dominant “handedness”, butter the bread, etc.
- Small portions are usually best
- Glasses should not be completely filled with beverage—refilling smaller amounts is generally better
- Finger foods might be indicated for residents who forget how to eat with silverware
- Encourage independence—sometimes the resident will begin eating once you make the first move by lifting a spoonful of food to her mouth
- It is often easier to eat from a bowl than off a plate
- Liquids should not be too hot or cold
- Omit foods that are hard to chew or swallow, such as nuts, popcorn, peanut butter, hard candy, raw vegetables
- Learn the Heimlich maneuver and use it if the resident gets choked on solid food to the point of severely restricting air flow
- Use proper feeding techniques when feeding those with swallowing problems, such as:
  - proper positioning and body alignment
  - small bites
  - allow to chew thoroughly
  - offer sips of liquid frequently
  - check for food stored in the mouth
  - cue/remind to swallow
  - feed from the tip of a spoon instead of from the side
  - mechanical soft or pureed diet might be indicated
  - be patient and give the resident time to chew and swallow

Toileting

Toileting is not usually a problem for residents in the early stage of dementia, but it becomes more problematic as the disease progresses. Some residents need reminders to go to the bathroom. Others tend to become incontinent. Urinary incontinence usually begins first, most often at night. Then occasional bowel incontinence. Incontinence spreads into the daytime hours, occasional at first, becoming daily.

Every resident with dementia will eventually require assistance with toileting, if the dementia progresses far enough. Prompt, consistent care will help eliminate a variety of problems and promote general well-being. Some pointers to keep in mind include:

- Do not assume that incontinence is necessarily due to Alzheimer's or that it cannot be helped; it can be due to another disease or condition, such as UTI
- Report if incontinence worsens
- Be alert to signs that could signal the need to go to the bathroom, including pulling on clothing, picking at self, being restless, pacing, undressing
- Anticipate incontinence episodes and try to get the resident to the bathroom before incontinence occurs, if possible
- Be understanding when accidents occur
- When accidents do occur, be calm about it and don't blame the resident for doing it on purpose
- Remember that infections, medication side effects, and an enlarged prostate gland can cause problems with urination
- Remember that incontinence becomes more likely as dementia progresses, so expect it
- The resident should wear clothing that is easy to remove to avoid undue anxiety when going to the bathroom, or when changing/cleaning after incontinence
- Objects like planters, trash cans, and water pitchers, and places like closets, room corners, and other small, confined areas might be mistaken for toilets; remove those objects as feasible that could be mistaken for toilets
- Residents who are prone to incontinence or otherwise have toileting problems should have a bathroom nearby
- Limit fluids in the evening and night
- Avoid stimulants in the evening, as these make incontinence more likely at night
- Try to observe patterns to incontinence and quickly respond when the resident appears to need to go
- Sometimes a sign or illustration representing the bathroom or bathroom door might help reorient some dementia residents to the bathroom
- Routinely take resident to the bathroom to lessen the likelihood of incontinence
- Let incontinent, ambulatory residents use the bathroom, even if they have to use adult incontinent supplies, until they cannot use the bathroom anymore (such as when they fight the caregiver)
- Incontinence can be helped by activity, proper nutrition and good hydration

Ambulation

Ambulation means to *walk*, or move about. The ability to ambulate is essential to most activities and is the most important exercise for the promotion of good health. As with most ADLs, ambulation difficulties are not a concern in the early stage of dementia. But as dementia progresses, physical manifestations become more apparent, including problems with walking.

Increasingly, residents need the assistance of an ambulatory device, such as a cane or walker, or physical assistance of one or more caregivers. For proper care in regards to ambulation, consider these points:

- Don't try to discourage pacing or wandering; as long as they are safe and basic needs are met, wandering and pacing occupies the resident and attempts to prevent it can provoke anxiety episodes
- Daily activity is important, so assist as needed to participate
- The resident will not need much assistance with ambulation in the earlier stages, but reevaluate need for assistance PRN and provide as needed
- As dementia progresses, the resident will move slower, more deliberately, and take short, shuffling steps—be patient and don't rush her
- There will likely be an increased risk of falls, so evaluate for this, using an objective falls risk evaluation and mitigate as far as possible
- Keep the environment safe—no throw rugs, quickly wipe up spills, keep the temperature comfortable, hallways clear, straight and clear path to the bathroom
- Monitor condition of the resident's feet, as any blisters or other skin breakdown as well as decreased sensation (such as with diabetes) will be apt to cause pain, decreasing ambulation and increasing fall risk
- The resident in all likelihood will not always be compliant with use of assistive devices, so encourage use of them, realizing that she will probably forget to use the device; cueing/reminding is ongoing

Bathing

Bathing can be a scary, stressful, frightening event. The demented resident in later stages might misinterpret the undressing as assault. She loses her ability to understand even what a bath is and the importance of cleanliness. She may feel uncomfortable with someone helping with an intimate, private task. She may feel threatened, vulnerable, embarrassed, or simply be reacting to the suddenly cooler environment.

Bathing, as you may have noticed, can be the most stressful and difficult personal care task of all to complete—for both you and the resident. Follow these tips to help minimize disruptive behaviors during bath time and maximize compliance.

- Respect the privacy and dignity of the resident no matter what her level of comprehension of privacy and dignity is
- Know that the elderly do not usually need a shower or bath every day; why risk confrontation when you don't have to

- Bathe the resident at a time of day when she is most calm and agreeable
- Be consistent to bathe at the same time of the day
- Occupy her mind when bathing her, perhaps by telling a story or singing; activities of daily living should not be conducted in silence
- Undress the resident standing on one side of her, as opposed to standing in front
- Approach and follow through with the bath in a calm, nonthreatening way
- Offer frequent praise during the bath/shower (let them feed off your positive emotions)
- Don't feel or act rushed—the resident who feels hurried will be more likely to become agitated
- A sponge or bed bath might be a practical alternative to the more involved (and potentially unnerving) shower or tub bath
- Give a plausible reason for getting a shower that makes sense to the resident (i.e., “It's time to go to work.”)
- If feasible, promote independence by encouraging the resident to do for herself what she is capable of doing
- Sometimes the best time for a bath/shower is when the resident is already engaged in a similar activity, such as going to the bathroom
- Know which habits were more successful in the past; is a shower, tub bath, or bed bath most successful? Does she prefer day or night? Is she private or modest? Does she prefer a same sex caregiver? Etc.
- Be alert for signs of being frightened or agitation and work quickly to de-escalate
- Provide for safety (shower chair, non-slip floors, hold onto rails, etc.)
- Verify reasonable water temperature (if too hot or cold for you, it probably is for them as well)
- Make preparations in advance—get wash cloths, towels, and clothing ready and have safety issues already addressed
- Utilize the proper number of caregivers (in assisted living, usually one or two)
- Remember that a daily bath is not usually necessary, unless she is incontinent
- Do not shower the face, as this can be frightening and can provoke agitation
- Undress the resident slowly
- Slowly introduce the resident into the water
- Be patient and go slowly (however, don't take too long, as this increases the chance of agitation)
- Don't be confrontational—try again later is the resident absolutely refuses

Dressing

Proper, clean clothes can instill a sense of security and improve well-being and self-esteem. In short, it can make the resident *feel* better. Particularly in the early and middle stages of dementia, most residents can do at least some portion of dressing/undressing themselves. They might need nothing more than having their clothes laid out and proper cueing or reminders. These tips can improve the dressing experience:

- Promote independence as long as possible
- Respect privacy and dignity
- Offer cues and reminders

- Don't allow too many clothes in the drawers and closets; many choices can be very confusing
- Create a routine by putting on clothing in the same order each time
- Don't give too many choices, but allow the resident to choose clothing if able
- Clothing and shoes should be comfortable and attractive
- Be aware of dressing needs related to other acute or chronic illnesses, such as the need for soft shoes for diabetics, “TED” or support hose, etc.
- If the resident likes to wear the same clothes, try to get matching clothes so they can be rotated
- Be patient when helping or observing the resident getting dressed
- Change clothing as needed, especially after meals
- Evaluate those who undress frequently; sometimes they think it's time to go to bed, or they need to go to the bathroom, they are too hot, bored, etc.
- Past generations dressed and changed differently than we do today—be careful about needlessly imposing our values on them
- Minimize buttons and zippers; use elastic and Velcro when possible
- Dressing should be done as consistently and routinely as possible
- Tube socks can be practical and easier since there are no heels to line up
- Shoes should be nonslip variety
- Lay out clothes in an organized fashion
- Like the rest of us, residents with dementia will gain or lose weight over time; therefore, watch for how clothes fit and make adjustments as necessary
- Consider jogging suits, as they are easy to get in and out of, easy to clean, and practical for long-term care use
- Avoid pantyhose and slips unless the resident feels uncomfortable without them

Grooming

Good grooming can enhance appearance and self-concept. It promotes good health and helps control infections. Tellingly, a lack of grooming (becoming slack in appearance) is one of the first signs of dementia. The resident has a decreased concern for appearance and just forgets (or forgets how) to do her own grooming.

The four parts to grooming concern hair care, nail care, oral care, and shaving. Some good tips and pointers to keep in mind can be seen below:

- ***Hair care***:
  - should be done daily
  - evenly distributes oils and cleans the hair
  - gives you the chance to inspect the scalp
  - should incorporate at least thorough combing, picking, or brushing the hair
  - using the sink to wash the hair might be easier than washing in the shower
  - a trip to the facility or local beauty or barber shop might be an enjoyable visit and can be a routine, positive experience

- ***Nail care***:
    - nail care is one of the most neglected aspects of personal care
    - should be done routinely
    - helps the appearance of the hands
    - helps prevent injury and the spreading of infection through scratching
    - fingernail care can be done by any trained personal care worker
    - be alert for and report signs of infection, ingrown toenails, discolored spots or other lesions, or injury
    - toenails of the diabetic or circulation impaired resident should be trimmed only by a nurse or podiatrist (foot doctor); check your policy

- ***Oral care***:
    - if resistant, try to brush the front of the teeth (some is better than nothing)
    - should be done daily
    - brush teeth or clean dentures daily
    - along with nail care, it is often neglected in long-term care facilities
    - can help prevent infections
    - improves the taste and smell of food
    - increases appetite
    - observe for and report foul breath, mouth sores, refusing oral care, chipped, broken, or missing teeth, signs of neglected care, or suspected cavities

- ***Shaving***:
    - be careful when using a blade razor when the resident takes a blood thinner, such as aspirin or Warfarin medication (i.e., Coumadin)
    - electric razors should be checked by maintenance before use, especially if used around oxygen, because electric razors could pose a spark hazard
    - take your time in order to minimize the chance of nicking or irritating the skin

Transferring

Transferring is the act of getting up or moving from one place of sitting or lying to another. Common points of transfer are from the bed to a wheelchair (or wheelchair to bed), from chair to toilet (or toilet to chair), from the floor to a chair (after a resident falls), and from one chair to another.

Transferring becomes more necessary (and more difficult) as dementia progresses. The resident loses muscular coordination and the body slows and becomes weaker. She becomes more unstable and more likely to lose her balance and fall.

These pointers and reminders are good to remember as they will assist you to make the most of transferring with the least turmoil and physical stress:

- Observe for falls; the likelihood for falls and need for assistance with transferring increases in later dementia stages
- Be gentle—the skin of elderly residents is often quite fragile and tears easily

- Use a gait belt or other assistive device as needed (per facility protocol, of course)
- Use good body mechanics to minimize the risk of injury to yourself or the resident by following these tips:
    - hold the resident close to you, to keep the center of gravity close, lowering the strain on your lower back
    - keep your feet at least shoulder width apart (a wide base of support is far more stable than a stance that keeps your feet close together)
    - use your stronger muscle groups to lift (legs, arms, and shoulders)
    - although it is not possible to keep perfectly straight when squatting or stooping, be conscious of your body position and keep your back as straight as you can, using your stronger thigh muscles (quadriceps) to raise up
    - when arising from a stooped or squatting position, first take a few deep breaths, leaning your head forward (helps keep you from getting dizzy)
    - size up your load and do not underestimate the effort needed to transfer
    - tell the resident what you plan to do and how she can help
    - don't rush the transfer and allow the resident to help (helps prevent injury)
    - get assistance from other caregivers as needed

General tips for caregivers

In this section of this inservice, we offer valuable tips to help you, the caregiver, to give better care to the institutionalized resident with dementia. Of course, the degree to which you are able to implement any given tip will depend mostly on the nature and extent of the dementia related problem.

Allow time for the resident to adjust to the new surroundings

Residents with dementia do not adjust quickly to new surroundings. Admission to a long-term care facility is a psychosocial change that can be confusing and scary. Because of this, behaviors are often worse the first few days after admission than they were at home, or the last place the resident lived.

Entering a new residence requires a period of adjustment. Allow two to three weeks for things to settle down and the resident to acclimate to the change. If a mental test, such as the MMSE (Mini Mental State Exam) is to be done, it might be wise to wait during this adjustment period.

Medication safety is a major concern

Residents in long-term care facilities have many diagnoses, often requiring numerous medications. If a resident takes at least 6 different meds, one study purports that she has at least an 80% chance of a drug-on-drug interaction. Lots of residents take far more than 6 different meds, so it's easy to see how medication interactions happen.

The elderly are not as quick to metabolize the chemicals in meds, so there's an increased chance of over-medicating. Over (and under) medicating are commonly seen, but it's difficult to know what will work (and how much it takes) without at least some trial and error. Be aware of behavior changes when a new med is introduced, when a med is discontinued, or when the dosage or frequency changes.

Keep a positive attitude

Ever notice how a smile makes others smile? Our disposition—our moods, words, and body language—has a powerful influence on others, for good or bad. Your attitude, whether positive or negative, will “rub off” on others. Dementia residents are sensitive to emotions and they can “pick up” whatever attitude you portray.

Provide for the resident's safety

The resident with dementia often cannot distinguish a safe situation from an unsafe one. She is more likely to wander, pace, elope, and get hurt. She is more prone to accidents and injury as she cannot use rational thinking to help guide her behavior.

Providing for safety can incorporate a variety of interventions, such as monitoring for elopement, keeping hallways clear of obstacles, assisting with ambulation and transferring when needed, keeping hazardous materials out of reach, and so on.

Become a good student—the best teacher is time spent with the resident

As the personal caregiver who actively and directly engages the resident, you are in a better position than most anyone else when it comes to understanding the resident. Doctors have training in diagnoses and treatment. Nurses apply advanced levels of care. But because of your daily and frequent interaction with the resident, you know her better in some ways than other caregivers.

Most residents are in your facility for months. Many are are there for years. This allows you a lot of time to get to know the residents. You learn their idiosyncrasies and their personality traits. You know what ticks them off and what calms them down. You discover tips and techniques that work for one resident—and fail with another. Use this knowledge to your advantage. Learn with each encounter. Apply what you know and grow in your role.

Touch can be better than talk

The demented resident thrives on human touch and will respond better to emotion than to logic. This is because the portion of the brain that governs clear, coherent, logical, and consecutive thinking processes has been damaged. She is not able to think in a reasonable and normal manner. She can, however, perceive emotions.

The proper use of touch can convey warmth, acceptance, and caring. While touch can have the opposite effect on the combative or hostile resident, it is usually accepted with the same spirit in which it was given. When you need to redirect a resident, or calm the agitation in her, try to reach her on the emotional level. Touch can help you do just that.

Stay in control of your emotions... but do not try to control theirs

Emotions are a good thing, but they can be powerful. We might not be able to help how something makes us feel, but we can control what we do, or how we manifest those feelings. In every circumstance, strive to remain in control of your emotions. In long-term care, especially when dealing with difficult behaviors in residents with dementia, this can be a challenging task.

When you are dealing with problem residents, try to think of their troubled behaviors as a fire. Your job is not to try to put out the fire by dousing some kind of liquid on it. The water you think you are throwing on the fire sometimes turns out to be gasoline. Rather, *deflect* the heat. Turn it away. Work to control the *behavior*—not them.

Keep it simple

Residents with dementia aren't in the mood to solve world problems. They can't even handle their own. Tasks that were once simple to them are now a cause for bewilderment. The more complex the task, the more likely she'll become exasperated. Simple, uncomplicated commands with one command at a time works best.

Every behavior has a cause—try to find the cause of undesired behaviors

Everything we do, everything we say, everything we feel, and everything we are has an antecedent. That is, there is a reason, a cause for it. Even for dementia residents. Yes, many of their actions and responses are atypical or inappropriate, but there IS a cause for all behaviors. You might not be able to identify what it is that triggers a specific behavior or condition, but it's there. How does this help you?

This is how it helps: knowing that a behavior has a cause might spur you to look for it. You would be surprised how many behaviors you could alleviate (at least to some degree) if you knew what caused them. Disrobing in public, for instance, might be a signal that she has to go to the bathroom. Constant lip smacking or chewing motion could be a psychotropic medication problem.

Most often you will find no apparent cause and basically chalk up the behavior to "just one of those things" caused by the brain damage of progressing dementia. But at least you will have tried.

Objects suggest action

Residents often engage in behavior we find odd or even amusing. Most of their actions are harmless. It helps to understand that there is a rationale behind any behavior. In the case of middle dementia especially, residents will show repetitive actions that don't appear to be goal oriented. The desire is to engage in simple repetitive motor action.

Odd uses of items are more common after a stroke. The use begins with the generalization of what the object is usually for. As an example, a spoon is not used for eating (too specific), but is something used to dip, or scoop. The resident might use the spoon to scoop water out of a sink or dirt from a flower pot. A hair brush might be used to brush the house cat, the sofa, or carpet. She takes an object with a general application and makes an odd use of it.

Be careful what you allow residents to see on TV or hear on the radio

Residents with dementia have an increasingly diminished ability to sort fact from fiction, reality from fantasy. The wrong kind of television programming with intense visuals and driving music can start a behavioral chain reaction in some residents. Under no circumstances should residents watch violent or tense scenes. War documentaries, horror movies, tense thrillers, even modern animated sit-coms can initiate thought processes you'll spend the rest of your shift dealing with.

Use common sense and be creative when dealing with difficult behaviors

Residents are individuals. How they progress through the dementia process as well as the kinds of behaviors they exhibit are just as varied as the individuals themselves. It takes a combination of caregiver traits to care for residents with dementia. Certainly, common sense, as well as knowledge gained through sources such as this inservice, is invaluable in this care.

Knowledge and common sense, though, are not enough. You also need to be savvy enough to be creative. This fact becomes quite clear when you consider that the same intervention done the same way for the same behavior will not have the same outcome between different residents, and sometimes with the same resident on a different day!

Case in point: Both Sally and Jane have mid-stage Alzheimer's dementia. Both get agitated on a daily basis. Medications have limited effect. Sally responds positively to touch. Jane gets hostile and draws back when touched. You already know that bathing Jane is not possible without touching her. You will have to dig a little deeper in the creativity toy chest to find the combination of interventions that will work with her.

Involve the family

The fact that the resident does not live at home does not mean that the family does not want to be a part of her care. Many families would like to be more involved. They may already feel guilt for not being able (or willing) to take care of their loved one. Being actively associated with the care can lessen feelings of abandonment and strengthen the relationship. Sometimes they just don't know how to deal with behaviors or how to become involved. You can help them with this.

Tell them the tricks, tips, and techniques in caregiving that you've discovered that works with the resident. Involve them in activities. Perhaps it would be appropriate for the family to take the resident on an outing on occasion. Sometimes a family member can calm a resident when no one else can. Don't hesitate to call upon the family, where appropriate, to aid in your caregiving. After all, your goal for the resident is comfort, health, and keeping difficult behaviors to a minimum.

Routines are important

In early stages of Alzheimer's (or dementia in general) new experiences can be good for the resident. In time, however, new experiences to her can be disruptive and confusing. It is important by this time to have some routines already established. She will naturally be more likely to follow them when she needs them most. To have a “routine” means to have something consistent pretty much day after day. Routines can include:

- Similar meal times
- The same caregivers (constantly changing caregivers is very disruptive and disconcerting to residents—strive to maintain low turnover)
- Similar time for personal care, especially bathing, getting dressed, and toileting
- Similar time for appointments
- Administer medications and treatments at the same time daily
- Getting up and going to bed at the same time each day
- Similar time for family visits, outings with the family
- Activities at the same time

Follow the care plan

A care plan is more than some required form that somebody has to complete and sign. Care plans are devised to give an objective and thought-out way to give care to the resident. They can be helpful tools but, unfortunately, are seldom used. This should not be the case. Completed correctly and followed diligently, the care plan can guide your care in an efficient manner. It can also help a new caregiver, not yet being familiar with the resident, to "come up to speed" quickly.

Promote independence (but don't push)

As a general rule, independence is a good thing and caregivers do well to promote it. But it works out only if the resident is physically capable and mentally competent. Now independence is not an all-or-nothing proposition. Most residents need some degree of assistance, as they are neither fully independent nor completely dependent on assistance for a given task.

Continue to promote independence, especially in the early stages of dementia. Be observant for signs of frustration or confusion during a specific task. Encourage the resident to do what she can do and assist her with what she cannot do alone.

Do not argue—arguing is a lose-lose proposition

Remember that the resident with dementia cannot rationalize like normal thinking people can. Arguing involves reasoning, an ability she is losing daily. Instead of the dementia resident saying, "Oh, I understand the logic behind your request", she is way more likely to cuss you out, cry, spit, yell, or otherwise react emotionally. Appeal to her on an emotional level. If you argue, not only will she not comply with your request but you will then be dealing with escalating, problem behaviors. You will both lose.

Use distraction and diversion when necessary

What is distraction and diversion? *Distraction* is doing, saying, or offering something to change the resident's focus. Distraction might help the resident forget what's making her upset. Since all emotionally based behavior is essentially self-oriented, getting the focus off self and onto something else can change a behavior, even if only temporarily.

Diversion is the effort to get the resident involved in some other activity in order to occupy her mind and body. Music, family member intervention, therapy, activity, reading (if able) or being read to, a snack or meal time, or some activity of daily living could be the diversion needed to otherwise involve the resident.

Learn about the resident's past

We all have a past, of course, and who we are now is shaped to a great degree by our experiences. Learning about the resident's past—from the resident and the family—will help you understand her more as a person, not just as a resident. You may find out how she has coped with stresses in her life; use this to your advantage. The more you know about her pre-dementia state, the better you can tailor your care to meet her needs.

Reminisce

Most residents have at least some fond memories of the past. Learn something about the resident either from the resident herself or from the family. Amazingly, many residents well advanced in dementia remember many details about family life and careers, so play up on this. Many residents love to talk about the past. This is called *reminiscence*.

Use humor

We all like to laugh. The resident with dementia won't understand jokes, but she will be more likely to smile when someone smiles at her, and laugh when someone else laughs. She may not even understand why you smile or laugh, but may mimic you just the same. Your happy, joyful personality will rub off on her in a good way. So would any negative personality traits.

Be careful with reality orientation

Although being oriented to time, place, person, and all that is generally a good thing, it is not always a good thing to orient a disoriented, demented resident. For example, suppose your resident believes it's the year 1976 and thinks her husband is still alive. If you tell her that her husband died 8 years ago, she may mourn his death all over again. There's is no good reason to put her through a trauma that she is not able to handle. Date orientation is not that important for these residents.

Respect personal space

Each of us has a personal space, defined as that distance we need to be from another individual in order not to feel too close or violated. Personal space varies for the same individual, depending on the relationship one person has with another. Always respect your resident's personal space as much as possible.

Address the resident according to age—not as a child

Residents in your facility are not children. They are adults. They should be treated as such. It is condescending to speak to them as if they are children. It does not matter how much brain damage dementia has caused, what her IQ is, or whether or not she acts as a child. She is *not* a child and should not be addressed as if she was.

Maintain eye contact

When you speak to the resident, maintain eye contact with her. This conveys a sense of interest; you are focusing your attention on her and she is more likely to perceive that you are paying attention to her. You don't want to gaze, or glare, but do look at her when speaking.

Don't take behaviors personally

Remember that the resident with dementia suffers from a brain-destroying disease process, and so is not responsible for her actions. When they engage in behaviors that are difficult to handle, even directed towards you, think of their behavior in terms of something you can help them with—not something you should be offended about. In a nutshell, don't take personally what's done or said to you.

Adjust your communicating style

The resident with dementia will not show the same symptoms to the same degree every day. Some days she may seem more lucid, coherent, or "with it." You may need to alter your style of communicating based on day-to-day ability to comprehend/verbalize. For example, when she is more confused, you may need to provide more cueing and directing; when she is more alert, she may better understand your directions.

Watch for increased confusion

Oh yes, dementia is responsible for most of the confusion in long-term care facilities. But as you know by now, many things can cause confusion. Complicating the matter is the fact that several things can conspire together to make the resident more confused.

Never automatically assume that an increase in confusion or general decline in clinical status is the result of dementia only. Sensory declines, metabolic problems, malnutrition, dehydration, and a variety of other factors, including infections, such as urinary tract infections (UTI) and pneumonia are common reasons for exacerbations (flare-ups) of confusion.

Expect the resident's abilities to decline over time

Primary dementia (which includes Alzheimer's disease, Parkinson's, vascular dementia, and several others) is progressive and eventually terminal. The resident with dementia *will* get worse over time. The rate of decline varies between residents.
Some residents will decline smoothly, almost imperceptibly; others will "stair step" (sudden drops followed by periods of relative stability). Many will "hold their own" for months, sometimes years at a time before declining, but they *will* spiral downward eventually. Expect this to occur and adjust your care as necessary.

Know what the resident's abilities are

Knowing what the resident with dementia is capable of is one of the most important and basic aspects to providing proper care. From this you will know what she can and cannot do for herself and what you need to assist her with. Keep in mind that though she will need consistent and similar care most days, she will experience times in which she is more or less capable than the day before. Adjust your caregiving accordingly and be willing to accept increasingly limited abilities.

Meet the resident at her level of reality

It's easy to figure out what physical limitations the resident has. It's another issue altogether getting a handle on where she is emotionally and mentally. After initial assessments and ongoing caregiving, you begin to paint a pretty accurate picture as to where your resident is coming from on those levels. If she is happy believing something that is not true (i.e., thinking a family member is alive who really is not), don't sweat it. With long-term care dementia residents, don't sweat the small stuff. Health, comfort, enjoyment, and all the benefits of care in the facility is your goal. Do not engage the resident in unrealistic goals of any sort—physical, emotional, or mental.

Be sensitive and gentle

There's no need to be insensitive and rough. Pay attention to what the demented resident's needs are and assist to help meet those needs in a gentle and caring way. Of all the personal characteristics you can bring to your care, empathy (caring about the resident and doing something about it) is the most important.

Do not become impatient when answering the same question over and over

Dementia has extreme effects on a person's ability to remember. Many residents show their forgetfulness when they ask the same question (usually 1 to 3 different questions) over and over and over. Quite often, they'll ask the same question mere seconds after you satisfactorily answered it! Some personal caregivers believe the resident is trying to irritate them. Yes, it can be frustrating answering the same question over and over, but remember that they are not trying to “tick you off”, so try not to get or appear annoyed.

Respond to the emotion if speech is absent or inappropriate

Especially in later stages of dementia, it can be indeed challenging understanding what the resident is says or needs. Remember to look for verbal clues as aides in guiding your assessment, such as grimacing if in pain, or getting up and down when needing to go to the bathroom.

Support positive behaviors

Everyone likes to be praised for things done well, and those with dementia are no exception. Find something to praise the resident for even in the midst of trying experiences or difficult behaviors. Dementia residents are emotion-oriented. As praise always appeals to the emotions, you'll find it better to “shine the light” as opposed to “cursing the darkness”.

Manage problem behaviors

Most dementia residents will eventually manifest problem behaviors, some on a daily basis. In the section *Dealing With Difficult Behaviors* you will find behavior-specific advice, tips, and pointers to help you better manage undesired behavior.

Focus on the resident's moods and behaviors, rather than on the task itself

Sometimes we get so caught up in trying to complete a task (after all, they *do* have to eat, get a shower, take their meds, etc.) that we forget we're dealing with a person instead of a chore. You are guaranteed frustration if you focus on the task. Rather, focus on the resident in order to complete the task. Be attentive to her moods and behaviors and use them to your advantage to help you get the job done.

Respond to their requests

Don't ignore residents who have questions or make requests, even if what they want is unreasonable. For irrational or senseless requests, divert or redirect them to other activities. Don't make promises you can't keep. Do what you say you will do, as this builds trust faster than most anything else.

Give one instruction at a time

One of the hallmarks of dementia is the loss of the ability to *multi-task*, that is, to do more than one thing at a time. Or comprehend more than one question or statement at a time. Doing so will inevitably lead to confusion and sometimes frustration. You would not say, “Put on your pants, then put on your shirt, then your socks and then your shoes.” Instead you would say, “Put on your pants.” then (after she puts her pants on) “Put on your shirt,” and so on until finished. The trick is to break down commands in bite sized chunks, the comprehension equivalent to eating small portions one bite at a time.

Engage in activities

Residents with dementia need routine, but this does not mean they need to be bored. And they *will* get bored without something occupying their time. Reasonable stimulation of the senses through activities is good for both mind and body. You'll see positive returns in attitude, decreased difficult behaviors, and more restful sleep.

Engage a variety of stimuli, such as pets, music, being read to, whatever activities the individual is capable of, without over-stimulating. It's OK if the resident is not capable of recognizing what the “end goal” of an activity is, such as completing a coloring book page.

The lack of a goal may affect the quality of the activity, but the “busy work” will give her something constructive to do. The length of the activity should generally be related to the resident's energy level and not to accomplishing a set goal.

Don't expect immediate responses to requests

Give the resident extra time to respond to your questions or commands. Be patient! Those with memory impairment need a bit more time to process your statement or question in order to follow your command or come up with an answer.

Don't try to change the resident's mind unless she behaves inappropriately

The resident with dementia is far more likely to have delusions and hallucinations. They live in a world that in many respects is not real. Don't try to change her mind if she is set in believing something that isn't true. Allow her the peace of living in her world. Of course, the resident will often try to act on those beliefs. If she begins to act out in an inappropriate or antisocial way, then utilize measures appropriate for the behavior.

Help the resident maintain social contacts

Most residents have family and friends. They still recognize people from church or a social club. Some have been very active in the community. Encourage those whom the resident knows to visit and interact with her. Encourage as active a social life as is good for the resident. Maintaining family and social contacts will stimulate the mind, improve the mood, and provide a needed activity.

Don't expect rational behavior

A resident's ability to be rational begins to fade as dementia progresses. They are less able to respond to the environment in a typical fashion. Do not be caught off guard when they do not act in a given situation as a normal thinking person would. Also, expect that her own once-rational behavior will sooner or later take on irrational modes.

Expect the resident to fully lose her memory

Many (but not all) residents with dementia will fully lose their memories by the end stage of the disease. Once familiar family members, faces of friends and caregivers, simple activities they mastered in the past, basic bodily functions—these are now lost and once gone cannot be recalled.

Goal should be enjoyment, not achievement

There's nothing wrong with achievement, per sé. In fact, when undergoing therapy (speech, occupational, physical) achievement is crucial in regaining some lost function or overcoming new hurdles related to injuries or new conditions. Ordinarily, however, our goal for the resident is promoting good health and enjoyment of life—not striving to achieve goals and accomplishments.

Use "mirroring" techniques

Residents with dementia not only forget to do certain things, they forget *how* to do them. More often than not, they want to cooperate but just don't know how to do the task. Be a reflection in a mirror, as it were, by demonstrating to them how to do the task you want them to do. For example, you can pretend to brush your teeth to remind her how she can brush hers.

Avoid bombardment—this can cause a catastrophic reaction

We've touched on this already, but it's worth repeating in a different way. When speaking to the demented resident, take into account her ability to understand and process what you are saying. Be careful when making too many statements or requesting too much of her at once. Asking or demanding too much too quickly can precipitate difficult behaviors, and in some residents, can cause extreme frustration.

Be careful when asking questions

Answering questions requires more thinking than following a simple command. In the beginning stages of dementia, the resident can usually handle most questions without much difficulty. But as dementia progresses, the ability to process questions becomes more difficult, especially open-ended questions (those that require more than a simple “yes” or “no” answer or a choice between more than two options).

Closed-ended type questions are easier to think through. An closed-ended question requires a simple answer, such as “yes” or “no”. For instance, you could say, “Did you enjoy your lunch today?” as opposed to “Tell me what you thought about lunch.” Another example would be, “Do you want to wear the white blouse or the blue one?” Both require simple, one word answers, but the latter one also requires a choice between two options (what if she wanted neither?). Pay attention to the resident's ability to answer questions, and use them sparingly.

Plan activities they are interested in

Merely engaging in an activity is by itself a virtually meaningless endeavor. Activities should not be just a means to an end (satisfy state requirements, or get the resident “tired” so she will sleep at night), but should also be an end in itself.

An activity is far more beneficial if there is some correlation between the activity and the resident's interests, abilities, or past experiences. Women, for instance, often find solace simply in helping with some household chore they are familiar with, such as folding clothes.

Men usually have experience with tools, machinery, and the like. Obviously, men won't be toying around with real power drills or fixing old, beat up cars, but playing with “toy” versions of real objects they are familiar with is helpful.

Simple commands, short sentences

Unlike some of the sentences in this inservice, residents with dementia need you to keep it short and simple. The less her ability to comprehend and act upon what you say, the more you should strive to keep your sentences, commands, and requests as simple, direct, and easily understood as possible.

They can't read lips, but they can read your emotions

Animals will often respond more than your tone than your words. Human beings are even more sensitive to body language, voice tone, pitch, and other communication elements. Your demeanor and mannerisms reflect your attitude and residents can sense this. They are more likely to respond negatively to a harsh deportment than rationally to words themselves.

Always strive to be calm and monitor the tone of your voice. As dementia progresses these things become even more important, for as dementia progresses, residents become more emotionally fragile.

Don't speak about residents as if they are not present or cannot comprehend

Never assume that a resident cannot understand what you are saying, even if you are sure they can't. It is very undignified to talk about a resident (especially anything degrading) within earshot. Just ask yourself if you would be OK with what the caregiver was saying about you if you were in the resident's place.

Always practice the "Golden Rule"

You may well know the ***Golden Rule***: *Do unto others as you would have them do unto you*. Unfortunately, caregivers often treat residents as if they are objects, or a nuisance, rather than human beings made in God's image who are suffering a defacement of that image by a hideous disease process. In all situations, put yourself in the resident's place and ask yourself if you would like to be treated the way you are caring for the resident.

Lock up any item the resident should not consume

This would include medications, poisons or cleaning solutions, or any other liquid (or ingestible solid) the resident could mistake for food and swallow. Products that look like food or appear attractive for consuming could be ingested by a resident who is acting out of habit or repetitive motion.

Be aware of changing psychosocial changes

Elderly residents have lived and coped with many things. Changes in housing, death of spouse and other loved ones, loss of friends, sexual changes, loss of independence, inability to drive a vehicle, decreased ability to control bodily functions and increased dependence on caregivers—all these things have profound psychological impacts. These losses and changes can cause depression and remove the will to live. Seek nursing and medical advice and assistance when the resident suffers significant changes on any level.

Dealing with difficult behaviors

One of the most challenging aspects of providing care to dementia residents is dealing with difficult behaviors. *Difficult behaviors* is defined as any behavior that interferes with the caregiver's ability to give care, is socially unacceptable, or becomes a danger or threat to the resident or others. Such behaviors can range from mild to extreme. Nearly every type of mental symptom can be seen in dementia residents, from anxiety to sexual aggression, from profanity to delusions, from depression to stealing, suspicion, fear, hallucinations, and so on.

Residents cannot help their behavior, because those behaviors are extensions of the dementia disease process. Therefore they aren't going to be receptive to logical or moral thoughts about what they do. However, those behaviors must be controlled or managed. Your mental and physical health (as well as those around you) depend on it.

It is because of the difficult behaviors that OSHA (Occupational Safety and Health Administration) regards long-term care facilities as dangerous places to work. Dangerous for the resident, because problem behaviors make them more vulnerable to getting lost or hurt. Dangerous for the caregiver, as they are often at the receiving end of hostile behaviors. In fact, CNAs make up 90% of victims of verbal and physical assault from dementia residents.

Five categories of difficult or disruptive behavior

Cognitive—The resident acts out a behavior based on what she believes. If she is confused or disoriented, or has delusions or hallucinations, she will behave accordingly.

Character—The resident who has a violent past is more likely to bring violent behaviors into the facility. These behaviors are often more violent and the most difficult to control because they are firmly established and not just a byproduct of a disease process.

Illness based—A disease process can cause temporary or permanent behavior changes. Dementia, Parkinson's disease, and diabetes are examples of chronic diseases that can cause permanent or long term changes. Urinary tract infections (and other infections, as well) are frequent causes of temporary and reversible behavior changes, as are medication reactions and numerous other causes.

Substance abuse—Behavior issues are common with residents who used alcohol, tobacco, illicit drugs, or abused prescription drugs. Withdrawal symptoms can exacerbate behavior issues. Residents who smoked or drank alcohol prior to admission and who are forced to cut back or cease the habit are behavior risks.

Reactive—The resident's interaction with the environment can cause them to respond accordingly. If she senses hostility, is confused as to where she is, or has her routine upset, she very well might act out negative behaviors.

An important point before we get into specific pointers, tips, and interventions is that most of our recommendations will help, but because of the multitude of causes and the damage that dementia does to the brain, none are *guaranteed* to work. It usually takes a multi-pronged approach (combining behavior intervention with prevention and sometimes medication) to lessen or eliminate problem behaviors.

Before we get into specific problem behaviors, let's take a few moments and cover some general tips about how to deal with dementia residents who exhibit those behaviors. Some of these points are already familiar to you, as we have covered them to some degree in a previous section.

Special tips for challenging behaviors

Expect difficult and frustrating behaviors

Primary dementia will progress and the resident will become more demented with the passage of time. She will almost certainly act out disruptive or anti-social behaviors at some point. This is a result of increasing brain damage and should be expected. The expectation of mental and physical decline should get us thinking beforehand what measures we might take to help alleviate difficult behaviors before they appear on the radar screen. Predict behaviors and try to have some ideas in mind about dealing with the behavior before it occurs.

Activities are better than management of difficult behaviors

The resident who displays an unacceptable, disruptive, or harmful behavioral problem needs to cease the behavior. However, something else must fill the void. Otherwise, the behavior could start up again. Involve the resident in something that will take her mind off the stimulus for the behavior. It is far more satisfying to involve the resident in a neutral or useful activity rather than to try to manage difficult or dangerous behaviors.

Is the resident "high attention" or "low attention"?

Many residents demonstrate some type of repetitive behavior, either through speech, action, or both. A *low attention* resident will display the repetitive behavior usually no more than 30 minutes. The *high attention* resident, on the other hand, will continue the behavior until she runs out of time, objects, or is told to stop. It will be hard to keep her seated, especially if others are moving. Both low and high energy levels are seen in middle stage dementia residents.

The differentiation between low and high attention is important, because it is the high attention resident who will most likely tend to exhibit behavioral problems, partly because they find many objects in the environment that can be manipulated. They often do two motions at the same time, such as pacing while combing hair.

Work with the family

Cooperative, caring family members are crucial to any real long-term success in giving optimal care and minimizing difficult behaviors. Unfortunately, not all family members are loving and supportive. Families often expect the facility to change a resident's behavior. Sometimes they don't understand what dementia is as well as the fact that most dementia progresses over time.

We don't know all the family dynamics nor do we have a full sense of the relationships between resident and family. While some families very much love and are quite supportive of the resident and the care you give, others can be more difficult to deal with. Some families feel guilt over the loved one being placed in long-term care. Some do not feel a sense of attachment and seem more concerned about finances (and what they'll inherit when the resident dies). That's sad, but that's the way it is.

Behavioral problems must be managed

Difficult behaviors can be problematic for residents, family, staff members, and visitors. Such behaviors can be at least disruptive to routines, and physically harmful at worst. Problems that are not reduced, controlled, or managed can escalate out of control. Violence is often an end result with harm to a resident or a caregiver. Yelling, screaming, biting, scratching, hitting, kicking, and similar abuses are all too common.

Verbal and physical abuse from one resident to other residents and toward caregivers is very commonplace in long-term care. It should be expected with dementia residents and steps taken on an individual basis to lessen the frequency and severity of behaviors.

Behaviors are attempts to cope

Many behaviors are an attempt to try to make sense of a world that no longer makes sense. Residents with dementia are not able to process information the way they used to. Decreased memory, progressing inhibitions, loss of reasoning and decision capabilities, and loss of moral understanding make difficult behaviors more likely.

Don't take behaviors personally

The demented resident “acts out” behaviors. They “shoot from the hip” without stopping to think about the consequences of their actions. They act from emotion and environmental cues rather than from logic or deliberate, thoughtful action. They are acting out from under the influence of a disease process and truly cannot help what they are doing, so it is neither right nor helpful to get angry, impatient, or offended when these behaviors are directed at you. We must understand that these residents are not trying to “tick you off” and would certainly choose to have full control of their faculties if they had the choice.

Assess for the cause of behaviors

One of the first, most fundamental questions to ask about any problematic behavior is: “W*hy did she do that?”* Every behavior has a cause. In most cases, we might not ever be able to identify the cause, but often this is due to the fact that we don't look for a cause. We're too busy dealing with the daily issues and reacting to problem behaviors to take time for some good old fashioned sleuthing. This is to our detriment. Paying attention to possible environment cues and thinking through episodes of undesirable behaviors and factors that might have led to them can help us deal with them more quickly and perhaps even lessen their effects.

Pain is quite often the source of undesired behaviors. The resident with dementia or Alzheimer's is frequently unable to tell you that she is in pain. Look for secondary signs of pain, such as irritability, grimacing (or other facial cues), or sensitivity to touch (drawing back when handled or touched, acting as if being touched hurt).

Define the behavior we want to change or manage

It is hard to change a behavior without identifying it. Greater successes can be won in the battle of behaviors if at first we at least define exactly what the undesired behavior is. Is the resident sundowning? Is she combative? Does she curse or resist taking her medications? Does she hallucinate or experience delusions? Identify as specifically as possible the difficult behaviors you need to address. This is the first step towards a peaceful resolution.

Attempt to change only one bad behavior at a time

Quite often the resident presents with more than one unacceptable behavior at the same time. For instance, she might use foul language and yell while striking at the caregiver who is attempting to give her a shower. In this example you have three inappropriate behaviors—using foul language, yelling, and hitting the caregiver.

When you are faced with a barrage of bad behaviors, look for the most pressing problem and deal with that one first. In the above example, first quickly look for ways (diversion, calm voice, not invading personal space, protecting your body, etc.) that can get her to stop hitting. Then focus on the other, less immediate concerns. Trying to accomplish too much too quickly will overwhelm the resident.

Devise a plan to deal with stressful behaviors

Review the resident's chart (as thoroughly as you have permission in your facility) and become familiar with her diagnoses. Learn her idiosyncrasies, the peculiarities that make her what she is. If you have been around the resident for some time, you know her in some ways better than anyone else. Use this knowledge to your advantage, along with her overall behavior patterns and specific difficult behaviors, and work with the family, therapy, doctor, and nurse to develop, follow, and review care plans that address her dementia.

Provide escape routes for stressful behaviors

A pressure cooker needs a pressure relief valve to keep the cooker from exploding. As soon as you perceive an unacceptable behavior, work to diffuse the emotions behind that behavior. Use distraction, diversion, activities, or any number of tips, techniques, and solutions given in this inservice to reduce the pressure of the resident's building emotions. All too often we make the situation worse by our actions. Remember that we are the ones in control—not the resident with dementia.

Respond, reassure, and refocus

These three “R’s” can be applied in most undesirable behavioral situations. First, take stock of the behavior. Does the behavior pose a threat to the resident or someone else? Is it permissible in the facility, or is it unacceptable? Is it disruptive to other residents? Does it prevent the staff from doing their jobs?

Respond to the behavior by identifying what it is, acknowledging that you are paying attention to the resident. Reassure her that you are there for her and that you are going to help her. Refocus her if need be, diverting or redirecting her attention to another thought or activity.

Keep a sense of humor

It is said that laughter is the best medicine. A good sense of humor can definitely help to lighten your load and make your day more enjoyable. Caring for residents with dementia can be challenging and difficult, not to mention emotionally draining. Find something joyful, funny, or humorous in a situation and be willing to laugh at yourself, but be careful not to laugh at them. They may not correctly interpret your sense of humor and feel you are making fun of them.

Reconsider the care plan as conditions change

Dementia is not a static condition. It is dynamic, ever-changing, and progressive. Interventions that work today might not work tomorrow. Be attentive to changes in the resident's mental, emotional, and physical status. Change your plan of care as needed. Her condition overall might remain stable for awhile, but eventually it will change.

Nancy Mace and Peter Rabins, in their book *The 36-Hour Day*, advocate an ongoing method of care that they define as the 6 “r's”—Restrict, Reassess, Reconsider, Rechannel, Reassure, and Review. Let's take a quick look at each of these.

> **Restrict**—Try to get the resident to stop the undesirable behavior. This might involve coaxing, persuasion, or compromising, etc.
>
> **Reassess**—Real problems or complaints often contribute to behaviors, so try to find a reason for the behavior.
>
> **Reconsider**—They do not see things as we do; try to see the world through their eyes.
>
> **Rechannel**—Redirect their behavior to more acceptable outlets.
>
> **Reassure**—Praise their accomplishments and try to help them understand that you are there for them, remembering that fear drives much of their behavior.
>
> **Review**—What works now might not work later. Adapt and change as they change.

We’ve covered some general tips for managing difficult behaviors. Now let’s look at some specific behaviors along with pertinent facts, triggers, and tips for dealing with them. Please note that some techniques and interventions are similar for different problem behaviors. This is because some behaviors can have a similar cause or effect. And some interventions are helpful across a spectrum of behaviors.

Challenging behaviors in this section

- aggression
- agitation
- anger
- anxiety
- catastrophic reactions
- Combativeness
- demanding
- depression
- fear
- hallucinations and delusions
- hiding things
- inappropriate sexual behavior
- Inappropriate toileting
- paranoia
- profanity
- repetitive Behavior
- resisting or refusing care
- seasonal/holiday problems
- shadowing
- sleep problems
- stealing, rummaging, hoarding, foraging
- sundowning
- suspicion
- uncooperative
- verbal outbursts
- wandering

Aggression

Verbal and/or physical aggression is commonly seen in long-term care facilities. One study showed that 45% of residents exhibited aggressive behavior over 2 weeks. Around 25% of residents in the middle and late stages of dementia will exhibit them. 70% of them are directed against staff members, especially during staff/resident interactions, i.e., assisting with activities of daily living.

Extreme hostile behaviors can come on quickly and without warning. These physical outbursts can occur once or twice a week and require multiple caregivers to intervene in order to control the violent behavior. PRN medications are often necessary. Fortunately, the severity and frequency of extreme hostility and aggressiveness tends to decline as the dementia progresses. Following are some tips on getting a handle on aggression:

- Dementia is a major cause of aggressive behavior
- Most forms of aggression respond to behavioral interventions, but some will require medication therapy
- There are often several factors contributing to aggression
- Each cause of aggression requires its own responses and solutions
- Unexpressed and unrecognized pain can lead to aggression
- The elderly with dementia have a 65% chance of aggressive behavior
- Routines will help cut down on the type and severity of aggressive behaviors
- Report threatening behavior
- Try to redirect to some pleasurable activity
- Find the cause of the behavior and eliminate or change the circumstance, if possible

- If personal care causes aggressive behavior, try to schedule in the morning
- Make meal time, ADL assistance, med administration, and all other points of care as smooth and non-threatening as possible
- Watch employee aggression—can heighten resident aggression
- Aggression can be caused by frustration with the demands of an activity, misunderstanding of expectations, infections, and other illnesses
- Knowing what can cause aggression can help you know what to do about it: asking them to do anything that is confusing, demands with too many steps, being impatient, expectations too high, not being able to make themselves understood, feeling tired or sick, being in an unfamiliar situation or place
- Be calm and reassuring, not controlling, belittling, or condescending
- Be confident, showing no fear or intimidation, yet patient and controlled
- Avoid distractions when dealing with aggressive behavior
- Make eye contact
- Think about how much you care for this person—it can make you more empathetic
- Ask closed ended, yes or no questions
- Use touch to convey acceptance and reassurance, but only if allowed
- Try to give in or compromise as much as possible, walk with them if they want to walk, etc.
- Praise success
- May be a moment before aggression when agitation is noticed—act on this
- Distract the resident who shows wide swings of over-reacting, excessive crying, or laughing (these are not true emotions and can be very tiring)
- Don't boss the person around
- Don't punish or try to intimidate them
- Don't accuse the resident of engaging in the behavior on purpose
- Protect yourself
- Do not restrain the resident unless absolutely necessary (and only according to facility protocol) as this only increases aggressiveness, agitation, and irritation
- Don't argue—lost rational ability prevents the resident from thinking clearly, consecutively, or logically
- The aggressive resident is frequently frustrated by failure, so maintaining dignity for the resident is important, for the aggression is not personally motivated; the resident acts out of fear or frustration

Agitation

Agitation can be defined as irritability or an unpleasant state of increased tension. It can appear suddenly or build up gradually and can last anywhere from a few moments to months. Many caregivers have trouble telling the difference between agitation and anxiety. Both can involve physical symptoms, but agitation is far more likely to act out inappropriate behaviors. Anxiety is more an inward mental state of being, the amount of stress the resident feels.

There are four major problems that can cause agitation: medical and physical, environmental stress, sleep problems, and psychiatric. They are further detailed below:

Medical and physical causes of agitation

Infections
Poor nutrition
Dehydration
Constipation
Medication reactions
Over-sedation
Arthritis
Pain
Impaired senses
Many others

Environmental causes of agitation

Loud noises
Air temperature too hot or too cold
Television or radio (too loud, too stimulating)
Being left alone for long periods
Being around too many people
Too much activity, commotion

Sleep related causes of agitation

Not getting enough sleep
Drinking fluids before going to bed
Confusing day with night
Sundowning
Biological clock is damaged

Psychiatric causes of agitation

Psychosis
Anxiety
Depression
Anger
Aggression

Interesting and helpful pointers, reminders, and tips are listed below:

- Agitation can take on the form of restlessness, confusion, hostility, hyperactivity, pacing, cursing, constant demands, repetitive behaviors, stubbornness, verbal abuse, aggressiveness, combativeness, shouting, and virtually any other inappropriate or antisocial behavior
- Around half of all dementia residents in the middle and late stages will show symptoms of agitation
- FDA has not approved any specific medication for agitation
- Agitation is often manifested as (and known by the term) *restlessness*
- Infection, stress, pain, fear, and other stresses can cause agitation
- Minimize environmental extremes, as they can lead to confusion, hostility, and hyperactivity
- Agitated residents show emotional distress along with behavioral changes
- It tends to grow worse as dementia progresses
- Agitation is often the reason families seek long-term care solutions
- Psychosis is commonly seen; this is defined as a delusion or hallucination wherein the resident's thoughts or senses do not agree with reality
- Common delusions include believing someone has stolen private property, danger from criminals, spouse is unfaithful, and family members are impostors
- Paranoid delusions are delusions that lead to fear, anxiety, or insecurity
- Depression is common and can be seen in the resident who loses interest in things once enjoyed, feels guilty about things done in the past, and is sad
- Depressed residents need reassurance
- Agitation does not go away on its own; it needs some type of intervention
- Support from families can help relieve agitation
- Medications can help but should not be the first line of defense

Anger

We all recognize anger when we see it. In the demented elderly, the ability to rationally deal with the normal emotion of anger and the loss of ability to control angry impulses may lead the resident to act out those impulses. Many situations lead to anger, which often begins as frustration that builds when it's not relieved.

- Anger can arise spontaneously without warning or apparent cause in the resident with dementia
- Anger can turn into aggression when the resident cannot deconstruct the anger or when ignored by caregivers
- Acknowledge the resident's feelings
- Do not react with the same feelings—respond with calmness
- Do not shout or raise your voice
- Attempt to redirect to something more pleasant
- Anger or hostility can mask fear
- Depersonalize anger by addressing fear component if present

Anxiety

Anxiety is a state of mind that is manifested by symptoms of feeling nervous, shaky, worried, scared, fidgety, or afraid. It is worry that is often out of proportion to the cause, a way of thinking that can interfere with ADLs, also known as stress.

In normal, everyday life, the elderly have many reasonable concerns. Present illness, loss of loved ones, changing psychosocial states, such as moving into a long-term care facility, decreased ability to express or receive intimacy, even worry about that next surgery or fear of falling can cause the resident to feel sad. The continual and growing concern over these things can lead to anxiety.

In the earliest stage of dementia, the resident recognizes that she is losing her memory. An unknown or uncertain future, expectations of increasing care needs, embarrassment over declining health and perceived burden to the family—all can promote and heighten anxiety. The resident with dementia who is anxious might not be able to put into words why she feels anxious, even in the early stages of dementia. The resident might appear nervous or upset, perhaps tense.

- Identify things the resident might be concerned about
- If possible, alleviate the source of any fear that might cause the anxiety
- Reassure her that you are there for her
- Fear of the unknown can cause much anxiety, so routines can help by providing a reliable expectation
- Anxiety disorders are as common and real in the elderly as with younger people
- Anxiety and depression are often seen together—roughly half of those with major depression have anxiety, while a fourth of those with noted anxiety are also seen to have major depression
- Anxiety should be considered as a diagnosis if the resident has chest pain, diarrhea, sleep problems, shortness of breath, or palpitations, none of which explainable with physical conditions or diagnoses
- Anxiety is often difficult to separate from agitation, because the physical and psychological symptoms can be similar
- The resident (with or without dementia) is more likely to admit a physical problem than a psychological one, so assess and document symptoms carefully

Catastrophic reactions

Catastrophic reactions are “over the top” type reactions, an exaggerated form of over-reacting. They are outbursts of emotion, usually anger or agitation. Catastrophic reactions are very difficult to control or divert once they begin, so the best strategy is to prevent them in the first place.

- Triggers can include: criticism, certain people, too much noise, too much environmental stimuli or activity, too many demands, too many questions at once, difficult tasks, and feeling tired
- Catastrophic reaction is often one of the first signs a person has dementia; it is therefore often seen in the early stage

- Simplify the environment
- Reduce noise and the number of people in close proximity
- Remove from the stressful environment
- Try to identify patterns in the reactions
- Daily activity and exercise is important
- Limit choices
- Speak slowly and softly
- Avoid fatigue
- Make one demand at a time
- Make eye contact
- Complete one demand before moving on to the next
- Make directions clear and unambiguous
- Make slow movements, gentle handling/touch
- Distract with pleasurable activity
- Follow daily routines
- Do not try to reason with the person
- Tell the resident what she *can* do, not what she *can't*

Demanding behavior

One of the hallmarks of dementia as with any condition or illness that affects mental health is that the resident becomes more self-centered. When the resident becomes centered on self, she is more likely to be demanding.

Alzheimer's disease or other forms of progressive dementia eventually erases the person's individuality. Traits she once possessed are no longer seen. She may have been kind and understanding but is now selfish and demanding. The demanding resident acts as if she is the only one being cared for. Staff feel exasperated, feeling like they are called upon to be a slave or “gopher” (“go for this, go for that”).

- Demanding attitudes might have been present with the resident pre-dementia; if so, more likely to be present during dementia, especially earlier stage
- Keep your promises and do what you say you will do
- Try to help the resident understand that you are available and not ignoring her
- Check up on the resident frequently; sometimes you can lessen demanding behaviors if you take the lead and not wait until the resident demands attention

Depression

Depression occurs in at least 20-30% of Alzheimer's sufferers. Even though Alzheimer's itself is not curable and scarcely treatable, depression is not. With the right combination of interventions (psychotherapy, medicinal, spiritual, social, etc.) depression can often be alleviated. How would you know if the resident is depressed?

Signs of depression

Trouble sleeping (insomnia)

Sleeping too much (hypersomnia)

Feelings of helplessness or worthlessness

Frequent thoughts of death or suicide

Trouble concentrating

Feeling more tired than usual

Talking less than usual

Changing appetite

Recent significant weight loss or gain

Feeling guilty

Crying

Not wanting to interact with others

Appearing sad or withdrawn

You notice changes in behavior around certain people, situations, or time of day

- Activity is very important in breaking the grip of depression
- Increase in pleasant activities
- Surround with people, items, and activities the resident can enjoy
- A facility pet is a wonderful idea (studies show that pets can enhance a resident's sense of satisfaction and joy and promote mental and physical health
- Reminiscing can bring back pleasant memories, which can help counter depression
- Engage the resident in simple projects or activities within the resident's abilities and that can be done in small steps
- Be there for the resident and check on her frequently

Fear

Fear is the catalyst for many behavioral problems with dementia residents. You name it, the resident could fear it—loss of independence, loss of familiar environment and family, new routines, new activities, new caregivers, family members not coming to visit, etc. One of the best ways to intervene in cases of fear is to identify, if possible, the source of the fear. You can then tailor your interventions to the cause.

Tips for helping the dementia resident who is afraid:

- Promote independence as far as possible
- Reassure them, affirm your availability and protection
- Engage them in activities they enjoy
- Provide a security toy, anything special that can bring comfort
- Since nearly anything in the environment can be construed as threatening, it is not always possible to identify the source of fear, so divert or distract as needed
- Be careful with TV volume and choice of programs, as the dementia resident cannot

process the information properly and often confuses fantasy for reality
- Create and maintain a calm environment

Hallucinations and delusions

Hallucinations are rather common in dementia residents, occurring in some 20% of residents with Alzheimer's. Both hallucinations and delusions are perceptions that do not agree with reality. A *hallucination* is perceiving with the senses (sight, hearing, smelling, touching, or tasting) something that is not real. A *delusion* is perceiving with the mind (a belief) about something that is not true.

Both hallucinations and delusions are difficult to counter because they are real to the resident. The resident does not have the mental capacity to process reasonable and logical arguments that what she perceives is false. Try the tips below to maximize your success in dealing with residents who experience hallucinations and delusions.

- Don't argue about what they believe, see, hear, or otherwise perceive, because it is real to the resident
- Respond to their feelings, not to the actual object of the false perception
- Provide reassurance and comfort as needed
- Do not agree with resident (you confirm the false perception) and do not disagree, lest you become part of the problem, a "conspirator" as it were
- Sometimes a hallucination or delusion is based on something real in the present or in the past, so check it out
- Respond to the emotions and distract, redirect as needed
- Report threats to self or another
- Do not argue with the resident, as this is a "no win" situation for either of you
- Hallucinations and delusions might not be a construct of dementia, but could signal another problem; don't assume dementia, so report any new onset or worsening condition
- Do not show violent TV programs, as the resident cannot distinguish between fantasy and reality
- Document type of hallucination or delusion; this is important
- Don't tell the resident that she is just "imagining things" as this will not be helpful
- Check for environmental clues, as hallucinations and delusions are often a play on, or a misinterpretation of, existing objects, such as shadows, reflections, glare, mirrors, etc.
- Get rid of noises that might lead to altered perceptions
- Let her know you are there for her if she feels scared

Hiding things

Hiding things is commonplace with residents who are demented. The hidden object is often part of a collection (rummaging) of insignificant things of little or no real worth. There is usually a specific, familiar place in which the resident hides objects. This is understandable, because demented residents do well with routines. Hiding things in a familiar location is memorable; the hiding behavior is, in fact, a routine in its own right.

Recognize that the resident who hides things will often forget she did so. She may blame others for stealing the very thing she hid. Staff often take offense at this. We must not be angry with them, as this is frequently seen in demented residents with worsening memory problems.

Some pertinent tips and techniques for dealing with residents who hide things include:

- Limit places where things might be hidden
- Identify patterns, for the resident with dementia often hides similar items in the same place
- Do not try to reason with or scold the resident who hides things
- Boredom and agitation are primary motivators for this behavior
- Remember that they forget where they hid things; their "routine" automatically guides their next hiding episode
- It helps their self-esteem to blame others, so don't take it personally

Inappropriate sexual behavior

One of the most disconcerting behaviors in the long-term care resident is that of inappropriate sexual behavior. Masturbation, inappropriate touching, or verbalization of sexual desire directed at staff or other residents are frequently encountered. This can be embarrassing, to say the least.

As far as rights go, the right to sexual expression is inherent in the long-term care setting. Sex is considered acceptable by informed consent, but as dementia progresses, informed consent is no longer assumed. The resident has forgotten social rules of etiquette and appropriate conduct

One of the most interesting (and important!) aspects of inappropriate sexual behavior is that as dementia progresses, true sexual desire actually diminishes. Brain damage that occurs with dementia removes inhibitions that would normally kick in and moderate behavior. What used to be private, true sexual expression has become public, dementia controlled out-workings of the mind. To better handle inappropriate sexual behaviors, please consider the following:

- Sexual misconduct can be easily managed; coupled with aggression, it becomes more problematic
- Sexual aggression should be treated like other forms of aggression
- Do not sound demanding or angry
- Remember that inappropriate sexual expressions do not normally stem from a sexual desire, per sé
- Few dementia residents can actually complete a sex act
- Touching, undressing, self-fondling, and lewd, sexually charged comments in the dementia resident should always be managed, but never personalized, as if the resident knew what he or she was doing
- Try not to over react or become embarrassed
- Don't make the mistake of assuming that a person with dementia who acts out a behavior was like that in her pre-dementia days
- Be calm but firm when responding to sexual advances
- Some meds might help curb sexual aggressiveness

- Identify residents who are more likely to be sexually aggressive
- Decide how you might respond beforehand, to lessen the chance of being “caught off guard”
- Protect yourself from predation
- If the resident is touching herself, don't necessarily assume masturbation—see if she has to go to the bathroom, is trying to loosen tight fitting clothing, or other physical reason

Paranoia and Suspicion

Paranoia: traditionally used to mean any delusional state, now used mostly to mean an irrational, excessive fear or anxiety, even to the point of being psychotic (out of touch with reality). In the demented elderly, paranoia usually begins as a hallucination or delusion. A delusion is a belief not based in reality. The delusion itself could be harmless and benign, as in the case of the demented resident believing she is still fit to drive, or that a dead loved one is alive.

Paranoid delusions, however, are not harmless and benign. They lead to anxiety, fear, and insecurity. Common delusions that can lead to paranoid behavior include believing someone has stolen private property, believing that one is in danger from criminals, that the spouse is unfaithful, and that a family member is an impostor. Around one third of Alzheimer's sufferers experience paranoia at some point during the disease process.

Suspicion is an intuition, an impression, or a feeling that something might be so, misgiving about a perceived situation or incident. Not all suspicion is based on falsehood. The suspicion could be based on reality. But residents with dementia tend to get suspicious and accuse others without just cause.

Some good tips about paranoia and suspicion:

- The paranoid resident is overly focused on self and can be suspicious of the most innocent situations
- Don't take paranoid or suspicious behaviors personally
- Allow the resident to express their suspicions without arguing
- Don't ignore the suspicion; reassure the resident
- Try to alleviate the suspicion if possible; for example, if you are accused of stealing something, help the resident look for the lost item
- Sensory deficits (loss of sight, hearing, loss of touch sensation, etc.) can lead the resident to misconstrue reality
- Do not argue, do not try to orient to reality, and do not correct the paranoid or suspicious resident—distract or divert them to more favorable activities
- Be aware of environmental changes/cues that could increase the potential for paranoia or suspicion: lighting, noise, odors, different caregivers, stimuli overload, TV shows, even boredom
- Reassure them they are safe
- Help them to understand you are there to take care of them
- Keep to routines and minimize changing those routines
- Maintain good lighting

- Encourage activity and sufficient rest
- Keep activities to a minimum early in the morning or late in the evening
- Respond to the feelings behind the paranoia or suspicion

Profanity

The resident who in a better day might never have cursed can turn into a veritable potty mouth as a result of developing dementia. Profanity can be quite disconcerting, especially when directed in anger towards caregivers. Dementia arises from brain damage. The part of the brain that becomes damaged causes the resident to forget social skills.

It is easy to forget that the resident who uses unacceptable or socially inappropriate speech does so not from deliberation, but from a disease process. Knowing and appreciating this will help us better manage those who curse, utter racially charged epithets, use sexually explicit language, or name-calling. Read the following points:

- Agitation and anxiety often precipitates profanity; see those appropriate sections to learn more about how to deal with them
- It is interesting that profanity in the normal thinking or demented person is far more common in times of stress, anxiety, or other high emotion moments; de-escalate any action that might lead to profanity outbursts
- Remember that the disease process damages the part of the brain responsible for moral thinking, decision making, and impulse control; the resident thus affected is reacting from the brain damage, not from purposeful, thoughtful interchange
- Gently request that the resident not use harsh or foul language
- Appeal to their emotions (and your own) to get them to stop abusive language; tell them how those harsh words make you feel; they are more likely to respond positively to meek and calm tones as opposed to criticism or harsh retorts
- Try distraction and diversion when needed
- Do not reinforce the behavior by dwelling on it; sometimes when other methods have been unsuccessfully tried, it may be best to ignore the obscene language

Repetitive behavior

Some residents with dementia will engage in repetitive speech at some point during the course of the dementia disease process. It may be only a single word that's constantly repeated. It might be a song the resident sings—over and over. Maybe it's one or several questions that she asks you again and again.

In addition to repetitive speech, actions are also common. Repetitive behavior of any sort can be either useful or problematic. To determine which it is, ask yourself what the resident is trying to accomplish. In many repetitive motor actions the resident is just trying to manipulate the environment. The length of time a resident spends on the repetitive behavior is not dependent on accomplishing an end goal. The action stops when the resident runs out of energy, gets bored, is redirected, or told to stop.

You will notice that objects associated with repetitive behaviors always have an associated task (i.e., a comb is for combing the hair, and a telephone is for calling somebody). But the resident with dementia has a skewed sense of the purpose for the object. The comb, for example, might be used to repetitively comb the hair constantly. A resident might turn a door knob around and around, back and forth. A phone receiver could be picked up, then hung up. Picked up and put down. Over and over.

- Carefully observe that the repetitive speech does not indicate an unfulfilled basic physical or emotional need
- Remember that the resident with dementia who asks you the same question she just asked a minute ago means she probably does not even remember she has asked the question already, so don't be impatient with her
- Politely and patiently answer any question asked of you, no matter how many times it is asked
- Do not become irritated at repetitive speech
- Do not demonstrate an angry or irritated disposition
- Distract with a simple, repetitive activity, which will sometimes take the place of repetitive speech
- The resident just needs reassurance, especially with repetitive questions

Rummaging, foraging, hoarding, and stealing

Rummaging*:* Searching for something. Residents often go into other resident's rooms, looking through closets, drawers, and personal affects. Rummaging is often seen in the early and middle stages of Alzheimer's.

Foraging*:* Strictly speaking, looking for food. The foraging resident will *rummage* through other's belongings in search of something to eat or drink.

Hoarding*:* Collecting (from own possessions or from others) too many similar items or items that have little or no intrinsic value.

Stealing*:* Taking something belonging to someone else. Dementia residents do not understand the moral implications (they can't distinguish between right and wrong) of stealing. In fact, they may honestly believe the items they took belong to them.

Any of the above behaviors—rummaging, foraging, hoarding, or stealing—are often seen in combination. For example, the resident may collect newspapers (hoarding their own and stealing from others) and hide them in their room.

- These behaviors are often the result of the resident being bored or restless
- Hoarding and hiding are common with Alzheimer's
- Don't accuse or get angry if accused
- Keep valuables (belonging to residents or staff members) out of reach
- Provide a “safe drawer” or place where the resident can rummage through
- Keep in mind that residents who hoard tend to put things in the same place
- Residents tend to blame others for stealing their things when they themselves misplaced the items; this is common and the resident should not be excoriated for “forgetting” that

she hid her own stuff
- You can sometimes lessen their tension by “helping them look” for things that seem to be lost or misplaced

Seasonal/holiday problems

There are many factors that can affect behavior. One of the most overlooked involves the time of year. Times of the year, such as birthdays, anniversaries, and holidays, present special, but manageable, challenges for caregiving staff.

These times can be emotionally and physically beneficial for the resident, but they can also be bittersweet, depending on the memories that the experiences invoke and the activities involved in the celebration. The resident will not neatly process the events and may even quickly forget every detail of the holiday experience.

- Encourage the family to visit
- If family has not seen the resident recently, discuss recent changes in condition so that the family will not be caught off guard
- Unreal, unfulfilled, or undesired expectations on the part of the family can cause them to become more hesitant and anxious, which in turn can upset the resident
- Families should always be realistic in how much of a visit or outing the resident can enjoy
- Keep in mind that memories of the past and problems in the present often collide; a visit could prompt some behavioral problems
- The resident could become more confused due to altered routines that a family visit or outing causes
- The resident may become more tired, anxious, or more demanding than usual
- Try to avoid strange surroundings or people as much as possible
- Residents should not receive gifts that require a lot of thought or effort
- Be careful about giving gifts that could be broken or lost (breaking or losing items is common with dementia residents); gifts should be practical and inexpensive
- Avoid too much food, drink, people, or environment change—anything in excess

Shadowing

Shadowing is following the caregiver or another person wherever she goes. This is often seen in the early or middle stage of dementia, especially after first being admitted to the facility. When at home, the resident was in a familiar environment. Taken from home and admitted to a long-term care facility essentially uprooted the resident from everything familiar to her. She is likely overwhelmed by her new environment. She is likely insecure and anxious. Here are some tips for dealing with the shadowing resident:

- The resident will be more likely to shadow if she is scared or confused
- Shadowing is more common when first placed in an unfamiliar environment
- Shadowing is more likely if the caregiver is more familiar than the environment
- Reassure the resident

- Engage the resident in meaningful activities
- A caregiver “substitute”, such as a stuffed animal, real pet, or baby doll, can help ease the resident into her new surroundings and provide a sense of security
- Repetitive, harmless activities can offer a diversion

Sleep problems

Sleeping problems are common with dementia residents, especially in the middle and late stages. The resident might lose the ability to tell night from day. She could experience a host of environmental influences that interrupt or prevent sound sleeping. Her biological clock seems to be “reset” and the awake/sleep cycle is disturbed. The end result is frequent sleeping or naps during the day and wakefulness at night. Whatever the reason, sleeping problems can be helped with the right interventions, and, occasionally, with the assistance of the right meds.

- Encourage a good sleep environment—personal cleanliness, warm environmental temp, soothing music, sufficient blankets, dim lighting, quietness
- A recliner or chair might be more comfortable than a bed, especially if the resident has breathing difficulties
- Avoid heavy meals within several hours of bedtime
- Medications should be a last resort, though sleep meds can help, but not always, and they can actually make sleeping problems worse by making the resident more confused (therefore, use with caution)
- Appointments and trips should be made earlier in the day
- Make residents feel secure and protected
- Psychotropics, if indicated, can help take the edge off undesired or destructive behaviors that occur in conjunction with sleep loss or sleep disturbance
- Establish a bedtime routine
- Don't awaken too early, as she may go to sleep in the early evening and awaken in the middle of the night
- Limit caffeine and diuretics later in the day
- Though there is no known specific reason for the biological clock change in the awake/sleep cycle, the interruption is frequently only temporary
- Though naps themselves can be beneficial, try to decrease the frequency and duration of naps with activities
- An activity when sundowning might help calm the resident and give her something to do
- Resident should have restful hours just before bedtime to allow for “winding down”
- Don't forget any pain management that might be necessary, as pain is often implicated in loss of sleep

Sundowning

Sundowning is a cluster of symptoms the resident with dementia shows later in the day, somewhat corresponding with the sunset, hence the name. Peaking during the middle stage of Alzheimer's, the resident tends to become restless, irritable, confused, insecure, and agitated at around supper time.

The cause of sundowning is not known. What we do know are some facts and interventions that can help improve the symptoms and calm the resident.

- Many older adults have less need for sleep, but may fight it when getting sleepy
- They may not always be able to tell reality from dreams, may get up confused
- Sundowning tends to peak during middle stages of Alzheimer's
- Sundowning is not a disease itself; it usually accompanies dementia or delirium
- Keep lighting up, as reduced lighting can precipitate sundowning
- At this time of day, the resident is more likely to experience delusions or hallucinations
- Residents are usually more tired later in the day, so plan with this in mind
- Stimuli overload during the day, too much activity, or fatigue is more likely to lead to sundowning
- Routine noises, though, offer security, the lack of which can lead to anxiety at night
- Try to discover what makes sundowning worse and mitigate those factors
- Limit daytime naps; sleeping too much can worsen sundowning
- Light to moderate exercise or activity helps by occupying the mind and body
- Schedule more involved activities earlier in the day
- The environment should be calm, low noise level, and talking among staff should be kept at a normal tone, since much noise can precipitate sundowning
- Follow bedtime routine

Verbal outbursts, yelling

Few disruptive behaviors are as quickly attention getting as yelling. Sometimes verbal outbursts stem from increasing anger or frustration. Yelling out repetitive words or phrases is also seen. Some of the more common causative emotional and physical conditions are shown below:

Common potential causes of yelling

Anger

Fear

Boredom

Frustration

Hunger or thirst

Pain

Feeling tired (fatigue)

Constipation or impaction

Sensory impairment

Delirium

Anxiety

Depression

- As with any disruptive or challenging behavior, identifying a possible cause in a given situation can help you formulate suitable interventions, so if pain is the cause, give PRN pain med
- Let the resident know that the yelling is not appropriate, but don't expect her to understand the reasoning behind your claim
- Let them know how the behavior makes you feel (speak to the emotion)
- Do not approach from a moral standpoint, but rather an emotional point of view
- Redirect as necessary
- Be alert for sensory deprivation; encourage the resident to wear eye glasses, hearing aids, and dentures
- Ignore the speech if not disruptive or if already calming down

Wandering

Wandering is a common sign and can be potentially dangerous. It occurs in up to 50% of dementia cases and is most often seen in the middle stage. The two cardinal signs that a resident is a potential wanderer are disorientation and restlessness. First, it is important to assess for, and reduce or eliminate if possible, factors that might be cause disorientation and restlessness, and therefore wandering.

There are **four main categories of wanderers**, all having a purpose in origin.

1. Residents who are trying to escape
2. Residents who rummage
3. Residents who simply roam through the unit
4. Residents who visit

Factors that can lead to wandering:

Interruption in past routines
Hallucinations or delusions
Social isolation
Sleeping during the day, staying awake at night
Needing to go to the bathroom
Disorientation
Boredom
Anxiety
Being in pain or other physical problems
Too much noise

Weather changes

Looking for a lost object

Feeling hungry or thirsty

Unmet needs, such as companionship

Searching for someone or something familiar

Too much activity or other intense activities

Change in lighting

Unless there is potential harm and if causative factors have been ruled out, allow the resident to wander. Within the confines of a special care unit, if exit points in the building are secure and the resident is not able to leave the unit or facility, wandering by itself is harmless, assuming that she is not a high fall risk and the environment is safe. Keep in mind, though, that the wandering, ambulatory resident with dementia is almost always automatically a high elopement risk (high potential of leaving the building).

- Assisted living facilities should not use psychotropic medications or restraints to prevent wandering
- Psychotropic meds might be indicated for residents who wander as a result of hallucinations or delusions
- First assess the cause and potential elopement (flight risk) of the resident; complete a *Falls Risk Assessment*
- Consider a recreational therapist if available, as they can be key to dealing with wandering behaviors
- Try to find and eliminate if possible any known cause of the wandering
- It is not always possible (or necessary) to prevent wandering
- Virtually any activity that is safe is positive for the resident; allow her to wander if she is inside
- Use a monitoring bracelet; place on the wrist or ankle
- Try putting an alarm bracelet on a walker, inside a purse, or hide the bracelet in another object the resident takes with her if she is keen to ankle or wrist bracelets and tries to cut them off
- Consider a body, chair, or bed alarm (cord attached to clothing worn by the resident and to the chair or bed)
- Keep environment, both inside and outside, as safe as possible
- Keep door to special care unit locked
- Keep meds and other potentially unsafe products out of reach
- Assume that the ambulatory or mobile resident is capable of elopement
- Do not underestimate the resourcefulness of the resident; memory might be better than you think; do not allow them to see others punch key code numbers that will open doors to the unit
- Follow policies and procedures for monitoring residents to help prevent elopement
- Wandering can be especially bad just after admission to the facility, because the environment is unfamiliar; the resident is usually looking for something or someone

familiar, or for a safe and familiar environment

- A wanderer is usually looking for something, so always assume that the resident would leave the building if given the chance (***never*** assume the resident will not elope just because she had seemed content or had never attempted before)
- Involving the resident in planned activities or exercise, especially on a routine basis; this will help reduce the likelihood of wandering
- Don't try to prevent wandering or pacing; rather, provide a safe area but be sure to address potential causes of wandering as far as you can
- Try to limit daytime naps; this will decrease potential for nighttime wandering
- Wanderers very likely want to go home; reassure them that they *are* home
- Make sure basic human needs are being met: toileting, hygiene and grooming, companionship, security, nutrition/eating, physical activity, etc.
- Be aware of all exit points from the building

Should the resident wander out of the building or away from staff supervision while outside, finding her can be difficult. She probably will not call out and will not answer even if she could hear you. She might get stuck in a place she cannot escape and become vulnerable to exposure. She does not always leave physical clues. This is tragically seen when the wandering resident dies from hypothermia or dehydration.

What to do if the resident wanders away from the facility

- Know your facilities' policy as to what to do it she wanders away from the facility
- Become familiar with the environment immediately outside the building
- If the resident is missing, follow policy; call the police; search the environment
- Keep a recent photograph of the resident to assist police if necessary
- Keep unwashed article of resident's clothing for use by search-and-rescue dogs

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Thanks for taking this inservice! Understanding and applying the principles, tips and techniques outlined in this course will help you give your very best care to those who suffer from dementia.