Alzheimer’s disease is not the end of the road, it is the start of a new journey.

(Alzheimer’s Association)
Schenectady ARC Aging Committee

Mission and Vision Statements

Mission Statement
It is the mission of the Aging Committee to serve as an accessible and reliable resource for individuals with developmental disabilities, caregivers and staff at Schenectady ARC who require aging-related information, training and/or referral services.

Vision Statement
Individuals with developmental disabilities, caregivers and staff at Schenectady ARC will be knowledgeable of information, resources and services necessary to address aging-related needs.

Schenectady ARC’s Aging Committee has worked diligently to gather aging and dementia related information to educate all caregivers of the aging individuals we serve. A number of training opportunities are presented to staff within the agency to ensure they are well-equipped to assist individuals with these needs. The committee also recognized that there are many caregivers, in addition to staff employed by the agency, who could also benefit from the knowledge we have compiled. Therefore, this Caregiver Information packet has been developed to provide this vital information to anyone who cares for aging individuals with developmental disabilities.

The Aging Committee maintains a resource library of material associated with a number of aging related topics. The information compiled in this packet was gathered using these resources. Of these, the following resources were especially helpful and were consulted to obtain a majority of the information contained herein.

- “Aging with a Developmental Disability.” Schenectady ARC staff training presentation compiled by Tammie Morley, LCSW-R.
- Schenectady ARC Caregiver Support Group curriculum developed 2008 jointly between Schenectady ARC and the Alzheimer’s Association of Northeastern New York.
- Program in Aging and Developmental Disabilities, Rochester Master Training Institute curriculum, presented by Ronald Lucchino, PhD, Kathleen Bishop, PhD, and Laura Robinson, MPH, September 2006.

The Aging Committee also highly recommends that all caregivers read the novel, Still Alice by Lisa Genova (New York: Pocket Books 2007). This is a fictional story written from the perspective of a woman diagnosed with early onset Alzheimer’s Disease. Although fiction, Ms. Genova holds a Ph.D. in neuroscience from Harvard and conducted significant research into the disease to portray what is believed to be an extremely realistic view of Alzheimer’s from the perspective of the person who is diagnosed with it. The book has been endorsed by the Alzheimer’s Association and Ms. Genova is now an online columnist for the National Alzheimer’s Association. You will notice some quotes from the book interspersed throughout this packet, in the hopes that it will provide a different perspective on the information presented.
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**General Aging Information**

See Environmental Considerations (pages 22-28) for ways to compensate for aging related changes.

The most important factors to combat aging include:

- **Diet**
- **Physical exercise:** Bones, muscles & coordination are impacted by a lack of exercise.
- **Mental exercise:** Helps to increase the neuropathways and stave off dementia symptoms.
- **Attitude/Self-esteem:** Appearance affects attitude! Grooming, being nicely dressed and other positive self-image actions can have a big impact.
- **Environment:** The more the person is able to do for themselves, the better they will age.

For everyone, aging causes changes to the cells of the body. These cells start to diminish faster than the body can replace them, causing the body to begin to slow down. Similar to a new car that runs smoothly with little maintenance or repair, as time goes on, repairs are needed to maintain function. Eventually, the parts wear out faster than the repairs occur and the car is less able to function properly. Below are some of the aging related changes that can affect everyone as we get older.

- **Age related VISION changes:**
  - Reduced ability to tolerate glare (shiny, polished areas): This includes shiny surfaces of flooring, furniture, walls, etc.
  - Reduced ability to adapt to the dark (difficulty adjusting when going from lighted to dark areas). Motion lights are very helpful with increasing vision and reducing falls.
  - Takes longer for the eyes to focus on objects at different distances, for example, going from looking at a book to looking across the room.
  - Reduced depth perception (ability to judge distance). This may affect crossing thresholds, using stairs, etc.
  - Reduced ability to distinguish shades of green & blue.
  - Presbyopia or farsightedness (trouble seeing close up).
  - Signs that a person may be having visual concerns: Look for changes such as squinting, eye rubbing, shutting or covering eyes, tilting or thrusting the head, stumbling, hesitancy on steps or curbs, holding reading material closer than usual, refusing to participate in activities they used to enjoy or sitting closer to objects than usual.

- **Age related HEARING changes:**
  - Loss in ability to hear or differentiate between sounds.
  - Decreased ability to hear high frequencies (females, children, words beginning with ‘st’).
  - Buzzing/Ringing: This can sometimes lead to auditory hallucinations (“hearing things”).
  - Reduced ability to maintain balance (they slow down, get up slower, are more cautious).
  - Potential symptoms of hearing loss: loud TV volume, responding inappropriately to questions, confusion in noisy situations, blaming hearing difficulties on others (accusing them of whispering/mumbling), head banging or isolating themselves.
  - Because some people with developmental disabilities already have communication limitations, a small amount of hearing loss can have the affect of a severe loss for them.
  - People with Down’s Syndrome may experience hearing loss in their twenties or younger (possibly due to having frequent middle ear infections due to having narrower ear canals).
Combined effects due to aging related **VISUAL AND HEARING** changes:
- Slowing of the ability to recall or remember things.
- Interference with short term memory processing.
- Slowing of cognitive function (brain’s ability to process & respond to information).
- Reduced ability to process multi-sensory input (sensory overload; too much information).
  
  Example: In a busy situation, such as the mall, it can be difficult for an older person to process what is going on around them. The noise, glare, busy visual field, etc. can all combine to become too overwhelming and prevent their brains from accurately processing information. **Some day programs and residences can be overly stimulating and behavioral concerns may increase (sleeping as a way to get away from the stimulation, refusing to go to program, etc.).**

Age related changes in **TASTE/SMELL**
- Taste and smell are connected. Most taste really comes from odors.
- Between the age of 40-50 for women and 50-60 for men, the number of taste buds start to decrease, while the taste buds that remain start to atrophy (lose mass).
- Any decrease in taste and smell can lessen interest and enjoyment in eating. When a person’s sense of smell is decreased, they may become less aware of personal hygiene.
- The reduced ability to smell and taste can cause a reduced appetite. As a person ages, their ability to identify and differentiate flavors and seasonings is decreased due to the loss of receptor cells in the tongue, resulting in decreased appeal and enjoyment of food.
- There is often a decrease in production of saliva, resulting in difficulty swallowing, increased dental problems and less efficient digestion. Difficulty with chewing and swallowing can limit food choices, resulting in the consumption of fewer calories, protein, nutrients, etc.
- Medications can change the taste of foods.
- Sense of smell may be lost due to the loss of nerve endings in the nose.
- The ability to smell also affects safety and enjoyment. We are able to detect certain dangers, such as spoiled food, noxious gases and smoke with our sense of smell.

Age related changes in the **DIGESTIVE SYSTEM**:
- Mouth: poor fitting dentures (due to jawbone loss), difficulty chewing, dryness in mouth due to reduced saliva, recessed gums, and loss of smell all make eating less pleasurable and weight loss or malnutrition more of a concern.
- Esophagus: Muscles weaken making it more difficult to swallow food (encourage person to drink fluids to push the food down); Increased acid reflux.
- Intestines: Mild to moderate constipation is common as the intestines slow down. This increases the need for water & fiber in diet. Decreased gastric secretions affect absorption of some nutrients.
- Don’t feel thirsty as easily, leading to a decrease in fluid intake and an increased potential for dehydration (symptoms of which can very closely mimic dementia).
- Stomach muscles don’t stretch as well and foods reach the end of the stomach more quickly, signaling the brain that the stomach is full without eating the desired amount of food. Smaller, more frequent meals can be helpful.
• Age related changes in **SKIN & PAIN**
  o As a person ages, they have a reduction in their ability to sense pain, vibration, cold, heat, pressure and touch.
  o Older people tend to have a higher threshold for pain. Touch sensitivity and ability to detect pain decreases with age.
  o Reduced fat under the skin increases the potential for bed sores and can cause the loss of body heat quicker in the cold, resulting in possible hypothermia.
  o Reduced oil glands can cause dry skin/itching leading to scratching and skin infections.
  o Reduced sweat glands can cause a decrease in perspiration and therefore less ability to regulate body temperature. Elderly people feel cold much quicker (even at a normal room temperature). Extreme changes in temperature are not tolerated well and increase the risk of injuries or hypothermia. Conversely, they are also less likely to feel hot, increasing the potential for heat stroke or burning.
  o Touch may no longer be pleasurable, as it may cause pain and/or bruising. Older people sometimes feel that they are touch deprived, because of the fear they might get hurt.

• Age related changes in **SLEEP**:
  o As you age, you need 6-8 hours of sleep per night.
  o People tend to get less quality sleep (spend less time in deep sleep) as they age, thus causing them to nap more during the day.

• Age related changes in **HORMONES**:
  o Experience decreased thyroid function, which can cause low body temperature and dementia-like symptoms. It is important to check thyroid levels even if the person is already on thyroid medication, as the levels change with age and medications can have different effects on the body as it ages.
  o Menopause (decreased estrogen): Causes behavioral changes, depression, bone loss, and possible short-term memory impairment.
  o Insulin: Age can cause an increase in insulin resistance.

• Age related changes in **EXCRETORY SYSTEM**:
  o Reduced bladder size increases the frequency of urinating.
  o Reduced muscle tone and strength of bladder contractions may cause them not to void all at once.
  o Increased frequency of bladder infections, decreased urinary control and increased incontinence.
  o Incontinence: Loss of bowel or bladder control often occurs with progression of Dementia; Individual may also forget where the bathroom is located.

• Other age related changes:
  o Blood pressure reflex slows (takes longer to regain blood pressure when standing). Medications can also compound this problem. Have the person get up slowly and give them something to hold onto until their blood pressure has stabilized.
  o Loss of muscle mass can lead to weakness, increased falls and decreased activity. Exercise can help retain muscle mass and strength.
  o Bone loss: Osteoporosis can cause pain, increased fractures and loss in height. Loss in jaw bone can also lead to dentures not fitting properly.
Medications and Aging

Medications are not typically tested on the aging population, so their effects on this segment of the population are not well understood. Pharmaceutical companies must test medications on the “average” population but not on the aged. The only way concerns are discovered is by doctors reporting adverse reactions to the companies.

Why are medications a concern?

The typical aging person takes an average of 7 prescription medications per day, causing an increased risk of adverse drug to drug interactions.

As we age, medications last longer in the body, take longer to absorb and/or be eliminated and therefore cause higher levels of medication in the bloodstream. The half-life of medications (length of time the medication stays in the body) increases with a person’s age. It also takes longer for the medication to reach the therapeutic dose. Due to these factors, a medication prescribed at the dosing range typical for a young, healthy person, may cause an overdose in the aging person. The medication may not have reached the peak efficiency in an elderly person by the time the next dose is taken. This leads to a markedly increased risk of adverse drug reactions and overdosing concerns. Therefore, an aging person may need smaller doses more often or a longer time between doses to prevent this concern.

Adverse Drug Reactions can mask or mimic other diseases or disorders, including dementia. Often, dementia-like symptoms are the result of adverse drug reactions. When an elderly person begins to develop dementia symptoms, a thorough review of their medications should be done to ensure that an adverse drug reaction isn't causing the dementia. Being dehydrated can also exacerbate these symptoms, as more medication gets stored in the blood since there isn’t as much water to flush it out.

Medical Appointments

As a caregiver, it is important to prepare for each doctor's appointment. The physician will want to know about any new or changing symptoms to better understand what is going on with the person. Below is a checklist of areas to consider prior to attending a medical appointment:

Caregiver's Checklist for Medical Appointments

- Medications
  - Side effects
  - Problems taking medications
- Nutrition
  - Weight Loss/Gain
  - Poor Eating Habits
  - Eating more/less food than usual or skipping meals
- Hearing/Vision concerns
- Sleep
  - Waking at night
  - Sleeping during day
  - More confused at night
- Challenging Behaviors
  - Agitation
  - Aggression
  - Wandering
  - Withdrawal
- Future Planning
  - Health Care Proxy
  - Living Will
  - Long Term Care
Dementia/Alzheimer’s Information:

Severe memory loss is NOT a normal part of aging!

Normal Aging versus Dementia (Alzheimer’s Disease)

<table>
<thead>
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<th>Person with Dementia</th>
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<tbody>
<tr>
<td>Forgets part of an experience, but often remembers later</td>
<td>Forgets whole experience and does not remember later</td>
</tr>
<tr>
<td>Recognizes people and places</td>
<td>Gradually unable to recognize people and places</td>
</tr>
<tr>
<td>Generally oriented</td>
<td>Gradually disoriented</td>
</tr>
</tbody>
</table>

Alzheimer’s disease is the most common form of dementia. Alzheimer’s results in impaired memory, thinking and behavior and will eventually result in death. Alzheimer’s is a progressive brain disorder. According to the Alzheimer’s Association, every 72 seconds, someone in America develops Alzheimer’s disease. By 2050, someone will develop Alzheimer’s every 33 seconds. An estimated 5.1 million people have Alzheimer’s Disease.

Alzheimer’s gradually destroys brain cells. A person with Alzheimer’s will eventually become unable to care for themselves. An excellent interactive tour of the effects of Alzheimer’s on the brain can be found at the following website: [http://www.alz.org/alzheimers_disease_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)

It is important to let the person do as much as possible for as long as possible for themselves. Studies have shown that people who are exposed to negative images of aging perform significantly worse on memory and balance tests and have a higher level of stress. (Leland, John. *NY Times*. 7 October 2009. Web 30 November 2010). When individuals are treated as children with phrases like “good girl” or “how are we feeling today?,” they tend to be more aggressive and less cooperative/receptive to care. If they were addressed as children, some of the patients in this study would show their irritation by grimacing, screaming, or refusing to do what was asked of them. It sends a message that the person is incompetent and “begins a downward spiral for older persons, who react with decreased self esteem, depression and withdrawal.” Conversely, this study also showed that people that had positive perceptions of aging lived 7.5 years longer. (Levy, B.R., Slade, M.D., Kunkel, S.R., and Kasl, S.V. *Longevity Increased by Positive Self-Perceptions of Aging*. Journal of Personality and Social Psychology 83: 261-270, 2002).

Another study (*Butler, Lanny. (2008) Therapeutic Approaches to Dementia*) revealed that it only takes three (3) days to render someone helpless by not allowing them to do anything for themselves. Having a person with Alzheimer's Disease do as much as possible for themselves, for as long as possible, will keep them healthier.

The following pages provide visual examples of Alzheimer’s/Dementia and how it physically affects a person’s brain.
Three stages of Dementia

Early Stage

- Short-term memory loss
- Confusion (gets lost easily/loses items)
- Mood/behavior/personality changes
- Routine Chores, job skills, “easy” tasks are challenging
- Loss of spontaneity, initiative
- Poor judgment
- Difficulty with communication begins
Middle Stage

- Increased memory loss and confusion.
- Shorter attention span
- Problems recognizing friends/family
- Repetition, restlessness, difficulty organizing thoughts
- Difficulty with ADL’s and communication
- Seizures can occur
- Nutrition - loss of appetite → weight loss

End Stage

- No capacity for self care
- Communication extremely limited
- Needs 24/7 care
- Does not recognize family/friends
- Significantly decreased motor activity
- Incontinence
- Complications from other health issues, which usually result in death
Changes in the Brain

- Large Brain
- Healthy Cells
- Normal Brain Activity

- Brain Shrinkage
- Plague Build up
- Cell Death
- Abnormal Brain Activity

Side by Side Comparison
Dementia Facts

What is Dementia?
- Dementia literally means loss of mind.
- Dementia is a decline in cognitive functioning or loss of mental function in several areas.
- Dementia results in impaired personal, social, and occupational functioning (ability to function in most areas of life).
- Dementia is persistent and progressive (will get worse).
- Dementia generally strikes the elderly population.
- Dementia interferes with activities of daily living (personal care tasks).
- Loss of initiative is often confused with laziness, but is one of the first indicators that someone is beginning to experience dementia symptoms.

What Areas are Affected by Dementia?
- Language/Communicative ability
- Memory
- Visual abilities
- Spatial abilities (ability to perceive two and three dimensions)
- Poor/decreased judgment
- Difficulty performing familiar tasks
- Disorientation of time and place
- Nutrition: loss of appetite $\rightarrow$ poor nutrition $\rightarrow$ weight loss

What are Some Symptoms of Dementia?
(This is NOT an all-inclusive list)
- Problems with abstract thinking
- Misplacing things
- Changes in mood/behavior
- Changes in personality
- Loss of initiative
- **Seizures may also occur in people with Down syndrome

What Conditions can cause dementia-like symptoms?
- Brain tumors
- Head injuries
- Nutritional deficiencies
- Hydrocephalus
- Infections (AIDS, meningitis, syphilis, Urinary Tract infections)
- Drug reactions-(Anti-acetylcholine drugs)
- Thyroid problems
- Dehydration
- Depression
How is Dementia Diagnosed?

A definitive 100% diagnosis can only be made at the time of autopsy. However, the following tests can be completed to help assess the person’s symptoms:
- Complete physical exam
- Neurological evaluation
- Psychological evaluation
- CT scan
- EEG
- Formal Psychiatric assessment

These tests can provide a reasonable diagnosis of dementia. In addition, it is important to have a well-documented progression of symptoms.

Note: For individuals with Down Syndrome, it has been suggested that a baseline video of their abilities be completed between the ages of 40-50 and then every 6 months to 1 year thereafter to compare for changes. This is the best way to see subtle changes and decline in skills. It is also a good tool to present to the physician to show the changes.

What is the Relationship between Down Syndrome and Dementia?

- The prevalence of Alzheimer’s type dementia in persons with Down syndrome exceeds that of the general population.
- Alzheimer's disease for person’s with Down Syndrome begins at a younger age and progresses much quicker than in the general population.
- It is believed that Alzheimer’s Disease may be related to the 21st chromosome. Those with Down’s Syndrome have an extra 21st chromosome in all cells. This could help to explain the close correlation between these two diseases.

<table>
<thead>
<tr>
<th>Non-Disabled Individuals</th>
<th>Disabled Individuals</th>
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<tbody>
<tr>
<td>Age 65-74 2%</td>
<td>Age 40 25%</td>
</tr>
<tr>
<td>Age 75-84 19%</td>
<td>Age 60+ 65%</td>
</tr>
<tr>
<td>Age 85+ 42%</td>
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Statistics provided by the Alzheimer's Association (www.alz.org)

Adults with developmental disabilities have the same risk as the general population of developing dementia, except those with Down Syndrome, who are at a much greater risk.

Those at greater risk for developing Alzheimer's include people who:
- Are 40+ years old and have Down's Syndrome
- Have had a severe or multiple head injuries
- Have a family history of Alzheimer's Disease
Caring for a Person with Dementia

“I struggle to find the words I want to say and often hear myself saying the wrong ones. I can’t confidently judge spatial distances, which means I drop things and fall down a lot and can get lost two blocks from my home. And my short-term memory is hanging on by a couple of frayed threads.” (Still Alice, Genova p. 251).

General Principles of Care for Persons with Dementia include:

• Each person experiences dementia differently.
• People will compensate for loss by using their remaining abilities.
• Understanding and empathy are vitally important.
• Understand and use different communication styles.
• Tailor the treatment to meet the person's needs and preferences.
• People with dementia are often overly affected by sensory changes.

We will attempt to give you tools to help you care for the person with dementia. Hopefully, this information will help you to better understand what your loved one may be experiencing and to feel better equipped to meet their needs. The information is divided into the following sections:

Behavior and Communication: There are reasons for every behavior. People do not display negative behaviors without an intended purpose. Often, these behaviors are the individual's way of attempting to communicate with those around them. Therefore, by understanding how dementia affects communication and learning and/or using different methods of communication, it is possible to decrease or eliminate many negative behaviors. This section also includes information specific to memory loss and confusion, as well as some helpful activity suggestions.

Environmental Considerations: The environment (the person's home, program setting, etc.) impacts the person's safety, mental status, all senses, information processing, behaviors, ambulation and independence. Altering a person's environment can enhance the individual's remaining skills, maintain their independence, decrease behaviors from fear or confusion, increase their safety and reduce sensory overload. Making changes to the environment is one of the easiest things a caregiver can do to improve the individual's quality of life.

Caregiver support: Caring for a loved one with dementia is very stressful. It is a demanding and emotionally draining experience. It is imperative that caregivers find time to care for themselves, as well as the person with dementia.
Behavior and Communication

Remember:

☑ All behavior has a purpose (it’s not just to make you crazy)!

☑ All behavior is a response to internal or external stimuli (real or perceived). The person is reacting to something they believe happened to them.

☑ All behavior is a form of communication.

What does it mean?

1. Something happens—a noise in the environment, a headache-stomachache, a hallucination. It can be internal or external. This is the STIMULI.

2. This stimuli causes a BEHAVIOR response. It may be an appropriate response or it may not, but either way it happens.

3. The caregiver, has a response to the person’s behavior. This is the CONSEQUENCE.

Example: if the Stimuli is a crack of lightening and crash of thunder, the person may become frightened and either begin screaming or running/walking around anxiously. If however, you the caregiver respond in a way that is soothing (not getting agitated yourself), you will very likely be able to significantly calm the person, deescalating the incident.
What’s Behind These Behaviors?

As the illness progresses, the person may be bewildered by events. For example, accusations of stealing may be an attempt to make sense of their inability to locate something or an unwillingness to accept that they have forgotten where they have put it.

Fear and frustration are major causes of behaviors. Examples include:

- Being unable to recognize people or places
- Sudden noises
- People approaching from behind
- Inability to communicate
- Personal space being violated while bathing, toileting or dressing
- Constant feelings of being lost, insecure or forgotten.
- Communication difficulties
- Being asked to respond to several questions at once
- Caregiver’s impatience, stress or irritability
- Person being scolded, confronted or contradicted
- Tasks not broken down into manageable steps or that are too difficult
- Instructions unclear or too complicated
- Frustration at not being able to do simple tasks that they used to do
- Not understanding why they need to do something or what is expected of them
- Changes in Routine
- The presence of a lot of people, a special event, distracting noise or activity
- Boredom, distress, restlessness, illness or pain may be expressed by anger, aggression or agitation
- Fatigue
- Disruptions in sleep patterns
- Physical discomfort
- Impaired vision or hearing
- Hallucinations
- Medication side effects
- Not remembering recent activities (when they last ate, that they already completed a task, etc.)

The bottom line is that the person’s brain has been damaged and this is what is making them behave differently than normal and most likely different from how they wish to act. As an adult with an illness, they deserve to be treated with dignity and respect.
Dangerous versus Frustrating Behavior

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<tr>
<th>Dangerous Behavior</th>
<th>versus</th>
<th>Frustrating Behavior</th>
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<tbody>
<tr>
<td>Wandering</td>
<td></td>
<td>Pacing/repetition</td>
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<tr>
<td>Aggression/combativeness</td>
<td></td>
<td>Shadowing/hoarding/hiding</td>
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<tr>
<td>Perception changes can lead to poor judgment</td>
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<td>Paranoia/suspiciousness</td>
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<td></td>
<td></td>
<td>Boldness/social inappropriateness</td>
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<td></td>
<td></td>
<td>Incontinence</td>
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Wandering: Why do they do it?
- Inactivity/boredom
- Searching for something from the past
- Frustration
- Being/feeling lost
- Feeling closed in
- Exercise/stimulation

Ways to Handle Wandering?
- Modify exits (camouflage exits, “child-proof” door handles)
- Install an alarm that is triggered when the door opens.
- Keep person active, busy (exercise) during the day, so they sleep better.
- Wandering paths: Create a safe place for them to wander so you don’t need to be on top of the person at all times. Create pathways where the person can continually walk in a circle or figure eight without dead ends. This keeps them safe and decreases the likelihood of frustration related behaviors. It also helps to decrease the caregiver’s stress.

Have the person carry identification and/or use a medical alert bracelet in case they are successful in leaving. Keep a recent photo available to show police if needed. Many caregivers also wear bracelets identifying them as such. If they have a medical emergency, people will be aware to check on the person they care for (available through the Alzheimer’s Association).

What is Sundowning?
- Sundowning is when the person’s symptoms worsen in the late afternoon or early evening. The brain is often more tired at this time of day.
- The sun setting can cast shadows in the environment which can be frightening for many people with dementia.
- While the exact cause of “Sundowners Syndrome” is not known, experts believe there are several contributing factors. These include physical and mental exhaustion (after a long day) and a shift in the “internal body clock” caused by the change from daylight to dark.
- Some people with Alzheimer's disease have trouble sleeping at night, which may contribute to their disorientation.
- Medication that can cause agitation or confusion also may contribute to this syndrome.

Tips to help with Sundowning:
- Ensuring a good night’s rest will help the person with dementia function better.
- Encourage physical activity during the day.
- Turn on lights before sunset and close curtains/blinds at dusk to minimize shadows and help to decrease confusion.
- If problems continue, ask the doctor for medication to aid in sleeping.
Behavior Management:

“We are going to have to change because they are unable to.” Moyra Jones

Below are a few suggestions to help manage some of the behaviors that may be displayed. The goal of behavior management should always be to reduce the person’s agitation.

- Try to figure out what’s behind the behavior? Look at what happened right before the behavior occurred. Were they trying to do something in particular? Had you just requested something from them?
- What can you control or change that might help?
- Respond to the issue and try to adapt to it to prevent it from reoccurring
- Attempt to complete tasks which cause outbursts at the time of day the person is at their best. For example, if they dislike bathing, try to schedule this task when they are most alert and rested.
- Be aware of the person’s limitations and don’t expect too much.
- Encourage independence by allowing the person to do as much for themselves as possible.
- Avoid confrontation whenever possible. Try using distraction or suggesting alternatives (sometimes getting them to do something unrelated will make them forget what they are angry about). In the later stages, a person will not be able to do 2 motor tasks at the same time. Therefore, if someone is agitated, providing them with a favorite item can distract them and stop their aggression. For example, it has been suggested that giving someone gum can stop a behavior because their brain cannot focus on chewing and having a behavior at the same time.
- Praise things which are done well and don’t criticize those that aren’t.
- Exercise may be a helpful preventive measure.
- The behavior of a person with dementia may be their only way of communicating. If the caregiver reacts in a calm manner to a difficult situation, there is a better chance of defusing the situation.
- Establishing a routine can bring order and structure to each day and studies have shown that people with Alzheimer’s Disease function much better when there is structure.
- Be aware of warning signs to anxiety or agitation such as restlessness, pacing, refusal to comply with requests, etc.
- Consider what is going on in the environment (i.e.: temperature, distractions, too much stimulation, shadows, etc.). Have the person’s needs been met (i.e.: are they hungry or thirsty, do they need to use the bathroom, etc)?
- Check to see if the person is in any kind of pain. Check blood sugar levels, blood pressure, etc. When someone is in pain, their eyes will dilate before they can tell you they’re in pain. If you suspect the person is ill or in pain, particularly if the aggression is uncharacteristic, it would be wise to consult a physician to rule out any medical concerns such as an infection or discomfort.
Communication

Communication can be affected by many things including:

- The physical changes the person is experiencing
- The person’s perceptions of things
- Environmental stimulation (i.e. background noise, distractions)
- Mood
- Previously existing disability
- New dementia symptoms

Verbal communication is only a small percentage of overall communication (see below). Be aware of not only what you are saying, but the way you are saying it and the body language you are using.

Communication Challenges: What you may see:

- Difficulty organizing words/thoughts
- Difficulty finding the right word
- Incorrect word substitutions (saying the wrong word)
- Reverting to native language (if English is their second language)
- Speaking less often
- Fluctuations or changes in communication ability throughout the day

“The words, the information . . . were like soap bubbles, the kind children blew out of those little plastic wands, on a windy day. They drifted away from her quickly and in dizzying directions, requiring enormous strain and concentration to track. And even if she managed to actually hold a number of them in her sight for some promising duration, it was invariably too soon that pop! They were gone, burst without obvious cause into oblivion, as if they’d never existed.” (Still Alice, Genova p. 241-242)
Caregivers may, inadvertently, cause communication difficulties for the person with dementia.

**Barriers WE Create**
- Our Tone of Voice. We might use a harsh tone because WE are in a hurry or stressed about something unrelated to the person with dementia, but they cannot decipher why we are upset.
- Not allowing enough time. Those with dementia often have a 90 second processing delay. So, from the time you speak to them, it takes them about 90 seconds to process and respond to what you said. If you repeat the question/statement within that 90 seconds, you restart the clock! (Butler, Lanny. (2008) Therapeutic Approaches to Dementia).
- Talking so fast that the person doesn't have time to understand what you are saying.
- Providing too much information (keep it simple).
- Assumptions: We assume the person understands us or that they know what we are referring to…but they may not.
- Using complex language. We sometimes use bigger words than are necessary.
- A lot of the time, we say a lot of nothing! We are all guilty of it! Figure out what is important for the person with dementia to know and understand and focus on that.

**General Communication Strategies**
- **Put yourself in their shoes**.
- Always use the person’s name and identify yourself and what you are there to do. For example, “Hi Jane, it’s Sue. It’s time for dinner. I’m going to help you to the table.”
- Approach them from the front. Let them see and hear you coming.
- Put yourself at their eye level and maintain eye contact throughout the conversation.
- Use short, simple and concrete sentences.
- Calmness, rationality, consistency and patience are essential.
- Use closed-ended questions (yes/no, two choices) to lessen the amount of abstract thinking the person needs to do.
- Sometimes offering a suggestion for what you think the person is trying to say when they are having word-finding difficulty can reduce their frustration and be therapeutic.
- Don’t take anything personally.
- Never talk about the person in front of them, as though they are not there.
- Use total communication. Your facial expression and body language will be more important than the words you speak.
- Respond to the emotional content of what they’re communicating, especially when the words don’t make sense.
- Supportive touch (back, head, or hand massage) can be very effective in soothing anxiety and frustration, unless the person doesn't like to be touched.
- Overemphasize your gestures and facial expressions to help the person understand your meaning.
- Allow extra time for processing and to express feelings. Remember the 90 second processing delay.
- A person with dementia will not be able to learn new tasks or concepts. However, they can be helped to utilize their remaining capabilities to the best of their ability. They will compensate for their losses by emphasizing their remaining abilities.
- Eliminate distractions.
- Demonstrate whenever possible.
- Repeat things in the exact same way.
- Use HUMOR!!!! This can be especially effective when tensions are running high.
Memory Loss/Confusion

Alzheimer's affects short term memory before long term memory (will remember the distant past better than the recent past).

Ways to decrease frustration over memory issues:
- Label things with pictures of the object. For example, put an older picture of the person (how they remember themselves) on their bedroom door, an actual picture of the bathroom on the bathroom door, pictures of items inside on drawers/cabinets, etc.
- Limit choices. Too many choices can get overwhelming & frustrating.
- Keep things consistent, such as furniture, personal items, etc. Don’t rearrange rooms.
- Maintain a regular schedule of activities at the same time/place each day. Alice says that her daily schedule “lay like bread crumbs that guided her through each day.” (Still Alice, Genova p. 144)
- Think safety: Use “child safety” tools (cabinet locks, plug covers, etc.).
- Help the person stay connected to their past. Keep photos and favorite items accessible. They often enjoy older TV shows or movies and their favorite music can be very soothing.
- Validation Therapy: Help maintain the person in the time they have regressed to. For example: The person calls you Beth (your name is Alice). Beth was a former caregiver. Don’t correct them, but ask about Beth and let them talk about her.

End-Stage Suggestions:
- Keep talking (even when you don’t get a response). Respond positively to any speech, even if it seems meaningless. Be on the lookout for non-verbal messages (i.e.: expressions, gestures, etc.).
- Always explain what you’re about to do before you do it.
- Use lots of soothing touch.
- Smell and touch are the last senses a person will lose, so incorporate them as much as possible.

Activities
- Therapeutic activity is thought to be most effective non-medical treatment for dementia. Not including them in activities leads to more rapid deterioration.
- Activity often serves as a distraction. It gives the mind something to focus on, rather than allowing it to be overwhelmed by confusion.
- Activity must be meaningful for the person. It should have relevance to the person’s likes, skills and abilities in order to be effective.
- Focus on the process, not the outcome. It's more important to participate than to do it right.
- Patience and a willingness to go with the flow are crucial.
- Make each day a special activity day, i.e. instead of being Monday, it may be Bingo day instead.
- MUSIC!! It can be appreciated and soothing regardless of disability. Holiday songs are familiar to everyone. Other recordings, such as familiar voices, stories, prayers, etc. can also be soothing.
- Dancing or walking helps to maintain strength/mobility for as long as possible.
- Sorting tasks such as sorting socks, silverware, etc. are often something the person will enjoy.
- Domestic tasks: Have them assist with chores as much as they are able.
- Maintain independence by slowly increasing their level of supervision. Avoid doing everything for them until absolutely necessary.
- Keep in mind deficits in fine motor skills (it gets harder to do activities involving small pieces).
Environmental Considerations:

Why look at the environment?
The environment impacts the person’s safety, mental status, their senses, information processing, behaviors, ambulation, and independence. The goal is to make the environment safer, familiar and to guide the individual through their routine. This is one of the easiest things you can do to improve the person’s quality of life.

- Environment influences every second of our waking time.
- We should be changing the environment, not trying to change the person.
- Changing the environment can help to decrease a person’s fear & confusion.
- Look at environmental changes before looking to develop a behavior plan. Changing the environment may eliminate the behaviors.

Stages of Environmental Modification for Dementia
1st Stage: Person is healthy & still mobile: Modify the home to assist the person to remain as independent as possible for as long as possible. Use reminders, pictures, fall prevention, color contrasts, adaptive equipment, etc.
2nd Stage: Person's judgment deteriorates; Caregiver needs to restrict some access/movement: Create safety zones & wandering paths; "childproof"; disguise/lock/alarm exits (see below).
3rd Stage: No longer mobile: Look at wheelchair accessibility, adaptive equipment.

Ways to prevent a person from accessing inappropriate items/areas or to encourage them to access appropriate items/areas

Preventing access
- Lock doors and windows. Placing a lock near the top or bottom of a door may prevent the person from noticing it and unlocking it. Use door knob covers or door stoppers.
- Use alarms on doors to alert you to attempts to exit.
- Disguise exits. For example, paint the door the same color as the wall so it blends in. Use a bookcase mural or poster over the door.
- Gates/Dutch doors. The person can still see you without entering room.
- Install a door to hide stairs or use gates to prevent falls.
- “Dead End” signs for doors. The person, especially if they used to drive, may avoid this sign.

Increasing Access
- Use double railings on stairs. Two railings help to prevent falls. The rail color should be different from the wall color to make them stand out so the person will notice and use them.
- Stairs: Steps should be noticeable. Contrast the backsplash color to the stair color. Add colored grip strips to stair edges. If stairs are all the same color, they look flat and the person can’t tell where each one ends/begins. Use good lighting on stairs and try to avoid casting shadows. Ensure appropriate stair depth (be cautious of carpeting). Stairs should be the same height/width to help establish a rhythm and prevent falls.
- Remove threshold changes (raised areas between rooms/areas) and throw rugs.
- Avoid clutter, especially in walking paths.
- Replace door knobs with lever handles, which are easier to open.
- Enhance doors you want them to use, like the bathroom door (make it a different color so it stands out. Put a sign/picture on the door indicating its purpose).
Physical Changes & Ways to Adapt

Below are some of the physical changes seen in aging individuals and those with dementia. Under each symptom/change, is a list of some environmental modifications that can be made to assist with each.

Arthritis & other joint diseases; Less ability to regulate body temperature; Loss of muscle mass:

- Mobility becomes more difficult. The person may begin shuffling when walking and will become more prone to falls.
- Temperature: Older people tend to feel colder. Be cautious of keeping the heat too low or the air conditioning too high. Provide sweaters/blankets if needed.
- Adaptive Equipment: Think about ease of use: Use Velcro instead of buttons/zippers; Install grab bars in bathrooms; Rocker light switches are easier to operate than regular switches; Use handle door openers instead of door knobs; Consider the weight of typical items (can something lighter be used)?
- Reduce Clutter: It can be a tripping hazard. Be aware of power cords. Clutter can also be over stimulating (visually, it is too much to take in).
- Fall Prevention: Increased muscle and bone loss, stiffness in joints, bouts of hypotension, medications and environmental factors all increase the risks for falls.
  - 30% of people over 65 and 50% over the age of 80, will fall in their home.
  - 40% of nursing home admissions are due to a break in a bone from a fall.
  - 25% of older people will die within 6 months of a broken bone.

The fear of falling may become disabling & interferes with social experiences and activities. This fear can also cause an increase in agitation and behavioral responses.

People often fall while getting out of bed, walking to the bathroom, between the hours of 6-8 pm or at the change of shift (in care facilities). The risk of the environment being a contributing factor in falls increases when the person has poor transfer or ambulation skills.

Fall prevention strategies:
- Remove throw rugs
- Use adequate lighting (to eliminate dark or shadowy areas)
- Use night lights in case the person gets up at night.
- Install hand rails & make sure they are a contrasting color to the wall so they stand out.
- Ensure shoes or slippers are form fitting (not loose).
- Eliminate changes in floor textures and thresholds (i.e.: avoid changes from a smooth floor to a metal threshold to a textured rug). Caregivers should try walking blindfolded through the home to see how their gait changes & what areas cause problems. Also, carpets should be wall-to-wall, high density, short loop pile.
- Stairs: Should all be same height & width, which helps the person to maintain a constant rhythm while walking. Ensure they are well lit, without significant shadows.
- Reduce medications, when possible, that may increase the person's risk of falls.
- Exercise will help to build muscle strength, thus decreasing the risk of falls.
- Learn about appropriate ambulation and transfer techniques to prevent injury to the individual and the caregiver.
- When there is a fall, review why it happened and look for ways to prevent it from reoccurring.
**Hearing Loss/changes:**  
**Hear bits & pieces; Lose ability to hear high frequency sounds;**  
**Difficulty tolerating background noise:**

- If the person is missing pieces of a conversation, they often get the meaning wrong. They may not be confused but, rather, they may not have heard all of what was said.
- Reduce background noises to improve what is heard. Try using quieter appliances. Don’t have them sit near heating ducts or air conditioners. Avoid having the radio or TV on in the background. In some cases, buzzing noises from lights/appliances can make those with dementia have a negative reaction.
- Avoid using a hearing aid in loud environments if you can’t reduce the background noise. The hearing aid will amplify ALL of the noise.
- Try to avoid or reduce sudden loud noises (i.e.: loud speakers/speakerphone). To someone with dementia, a loud speaker can be very confusing and scary. The person may not understand where the voice is coming from (paranoia).
- Soundproofing can be used to reduce echo & absorb noise. Use soft materials or fabrics to absorb background noises and decrease echoes. Carpeting is also helpful for this purpose.
- Use therapeutic sounds that they seem to enjoy such as favorite music, birds, ocean, etc.
- Consider that bone loss may make a hearing aid ill-fitting and painful which may lead them to refuse to wear it. Have the fit checked regularly.

**Vision:**  
**Decreasing visual acuity & field of vision; Depth perception decreases; Change in ability to distinguish colors; Cataracts or Glaucoma more common; May only have peripheral vision (have trouble seeing directly in front of them); Things look less clear or focused, often described as looking through yellow cellophane; Glare distorts vision & may be painful on the eyes.**

- **Color Contrasts:**
  - Color may be seen differently. Blues and greens may look the same. Keep this in mind when decorating or when asking the person to choose clothing.
  - The aging person will need more color contrast to tell where things are (i.e.: floor to walls to furniture; fixtures to walls/floor; tableware to table; counters to floor). For example: white walls, a white floor and white bathroom fixtures make it difficult for someone with visual concerns to tell where things are, as the white makes them all blend together; Use placemats of a different color to help the plate stand out from the table.
  - Written materials: Best if black ink on white or yellow paper.
  - Busy patterns, especially on floors, are difficult to tolerate. To those with dementia, large patterns on floors, walls, bedding, etc. may look like holes, scary objects, etc.
  - Use calming colors (pastels rather than primary colors).
  - Stairs: Handrails should stand out from wall (be a different color); stair color should be very different from wall color; contrast the backsplash color to the stair color; add color to the stair edges to differentiate each stair.

- **Light/Glare:** Various resources estimate that by the age of 60-70, a person will need 3-4 times as much light as they needed at age 20 to see just as well.
  - Use low gloss paint, wallpaper, floor waxes and flooring (avoid Pergo) or use carpeting.
  - Use window blinds or drapes at night.
  - Use fluorescent lights instead of incandescent; use "full spectrum" light bulbs.
  - Avoid too many mirrors, which can give false sensory info & cause glare.
  - Do not use exposed light bulbs (cover with white or translucent covers).
  - Use rope lights attached to the underside of the stair handrails to provide additional light on the steps.
• Holes/Shadows: Beware of shadows caused by inconsistent lighting. To those with dementia, they appear to be “black holes.” Individuals see dark areas (shadows/dark carpets, etc.) as holes and are afraid to go there (i.e.: checkerboard floors/dark rugs). Provide consistent lighting throughout the room. Use task/area lighting where necessary. Motion lights can also be helpful.

“She raced to the front hallway, but then stopped before she could reach the door. It was the strangest thing. There was a large hole in the floor just in front of the door. It spanned the width of the hallway and was about eight or nine feet in length, with nothing but the dark basement below it. It was impassable.” “The mail had just been delivered through the slot in the door, and it lay on top of the hole, somehow hovering there. It had to be balancing on an underlying beam or floorboard she couldn’t see.” “A noise at the front door woke her from her nap on the couch . . . Anna stood there with a big brown paper bag in one hand and a jumbled pile of mail in the other. She was standing on the hole!” “Alice walked over and crouched down. She put her hand on the hole. Only it wasn’t empty space she felt. She ran her fingers over the looped wool of a black rug. Her black hallway rug. It’d been there for years.” (Still Alice, Genova pp. 206-211)

Proprioception & Vestibular Systems: Give us a sense of where we are in space, allow for motor planning, movement sequencing & time activities.

• Warn the person before touching or moving them.
• Use strong touch and hugs; Weighted or heavy vests & blankets may be soothing, but use caution with those with osteoarthritis.
• Use controlled spaces with lots of cueing to help them have control over their environment. For example, use signs and pictures to identify things for them; limit access to unsafe areas.
• Provide opportunities to touch textures and objects. Set up calming environments without sensory overload to help them calm (i.e.: rocker/swing in a quiet, clear corner).
• Texture issues (behaviors like stripping, wearing only one or two things over and over) may be a tactile issue for them. Certain clothing may be uncomfortable to them. Let them wear what they want and work around it (wash them every night; buy more than one of a preferred item).
• Don’t fight rocking or wandering. Find a way to incorporate it (create a safe wandering path; get a rocking chair).
• Be patient and work on their fears one step at a time (i.e. if they have a fear of water, start with just washing their feet in the shower; try a sponge bath instead of a full shower).
How to accommodate Appetite and Feeding Issues

- Use seasonings. If taste buds have dulled, use additional seasonings to enhance flavor.
- Bake bread or cookies. Use food scented candles to stimulate appetite before meals.
- Change foods (they may not like their favorite food anymore). If they are resistant to certain foods, change the menu! Avoid hard to chew foods; Serve finger foods that are easier to handle.
- If they have behavioral reactions to certain foods/scents, be aware of and avoid these triggers.
- Simplify the process & be patient. Don't force feed the person or punish them for not eating.
- Memory/Emotion: Certain scents/tastes may trigger a memory which can cause an emotional reaction. Familiar, comforting foods or scents may help to increase their appetite.
- Swallowing difficulties often occur.
- Be alert for possible medical causes (medication side effects, disease, constipation, poor fitting dentures, dry mouth, etc.).
- Check the temperature of the food (they may not know to do so).
- Have water, juice & healthy snacks available.
- Texture: Texture may be unappetizing; Spice up food to try to make it more palatable.
- Use high sided bowls/plates to assist with maintaining independence.
- Those with dementia often become overwhelmed with too many food choices, forget to eat or think that they have already eaten.
- Focus on the meal, reducing any possible distractions.
- Describe the foods being served
- Use color contrasts to highlight plate/food. For example, use a placemat of a different color to make the plate stand out. Try to have different colored foods.
- Always put the same type of food in the same place on the plate (i.e.: meat, starch, vegetable). Try to serve meals at about the same time each day and keep seating consistent.
- Use only the utensils necessary for that meal. If they don't need a knife, don't give them one.
- Provide simple instructions to avoid confusing the person.
- The time may come when your loved one can no longer maintain the family’s mealtime routine. At this point, it may be best to feed them one-on-one to minimize any distractions to eating.

How to Prevent Dehydration:

- Offer fluids regularly.
- Have a beverage with the person, so they can mimic what they see you do.
- Use a straw if they are having difficulty drinking from a cup.
- Include foods such as Jello, soup, fresh or canned fruit, sherbet or flavored ices which have a high fluid content.
**Room by Room Suggestions**

**Bathroom**
- Place grab bars where the person tends to lean & ensure they are securely attached to a wall stud. Consider the person’s dominant hand when determining bar placement. Avoid bars that restrict tub access or those that slant downward at angle (these make it easier for the hand to slip). Remove the towel bar if they use it as a grab bar, as it is not stable.
- Fear of water is not uncommon: Use a handheld shower head & start at their feet, easing into it.
- Use a shower chair or bench in conjunction with a hand held shower head.
- To prevent burns from hot water: Mark the wall at the correct temperature; use an automatic temperature control device; reduce the temperature on the hot water heater.
- Contrast the toilet color to the wall/floor to make it stand out. If you can’t change the colors of your floor or toilet, use colored tape at the base of the toilet. Switch the toilet seat to one of a contrasting color (avoid ones with a pattern that could confuse the person).
- Flooring: Be cautious of marble flooring as it gets very slippery when wet. Avoid significant flooring patterns that can confuse the person or make them fearful.
- Lock up/hide chemicals/shampoo/medicine, razors, etc.
- Use non-slip mats in the tub/shower. Ensure bath rugs have non-skid backing.

**Incontinence Concerns in general:**
- Establish a routine for toileting.
- Limit fluid intake right before bedtime.
- Use a bedside commode if the person is unable to get to the bathroom in time.
- Use incontinence devices (i.e.: Attends) appropriately.

**Kitchen:**
- Remove stove knobs or use knob covers if they can’t use the stove. If they can still use the stove, highlight the “On” or temperature with brightly colored paint to make it easier to see. Ensure gas stove knobs cannot be accidentally turned on (without ignition).
- Unplug appliances you don’t want them to use or use appliance locks. Disable the garbage disposal or cover the switch.
- Single lever faucets may be confusing to those with dementia. If you want them to use the sink, use a regular, two handled faucet that indicates hot and cold. If not, a single lever faucet may be a deterrent. Remove the sink stopper to prevent accidental flooding.
- Lock up dangerous utensils (i.e.: knives) and chemicals.
- Create a “Safe Zone” where they can use items/be helpful. Leave safe, commonly used items where the person can easily find them.
- Label drawers/cabinets with pictures of what is inside to help them find things easier.
- May need to remove or hide waste baskets (i.e.: under sink) as the person may forage through the trash for something to eat.
- Use cabinet/appliance locks to prevent inappropriate consumption of foods or other products.
Bedroom:
- Keep in mind fall prevention. Beware of clutter, throw rugs, dust ruffles or overly long blankets.
- Contrast the bed covering & chairs to the wall & floor so they are obvious.
- Use adequate, non-glare lighting. Use task lighting, if needed.
- Bed alarms can alert you if they have gotten up.
- Ensure the purpose of the room is clear. Don’t have a lot of activities in the room other than the bed, so person knows this room is for sleeping. Keep bed clear of too many decorative items.
- Avoid bedding with busy or large patterns that could be scary or confusing to them.

Living Area:
- Help to keep them calm & connected by using pastels and keeping familiar objects around.
- Avoid busy patterns (i.e.: flowered wallpaper/furniture—person may try to pick flowers; vines may look like snakes, etc.)
- TV: Turn it down if you are trying to speak to the individual or it will become annoying background noise for them and will make it difficult for them to concentrate. Channel surfing can be a frustrating distraction (they may not understand the constantly changing voices or images).
- Lighting: Be aware of shadows. Use task lighting for activities if needed. The living room is often the room with the most inconsistent lighting (i.e.: lamps instead of ceiling lights). Aim for natural & consistent lighting.
- Furniture with arms that extend to the front edge of the seat can help the person to get up easier. Avoid furniture that is too low or too soft, which make it more difficult to stand up. Recliners are good as long as the person remembers how to use them. It may become dangerous if they don’t remember how to get out of it.
- Contrast the furniture to the walls and floor. Contrast the walls to the floor by making them different colors or using a different colored trim.

Exterior:
- The door to the house should be a different color from the house so the person can find it to come back inside.
- Be aware of height differences between the driveway, sidewalk, lawn & entryway.
- Safety first!! Include the patio/yard as a living area, but ensure it is safe. Allow for gardening if it is a favored activity. Use fences to prevent wandering. Be aware of pool and garage safety.
- Create non-slippery wandering paths outside. Be aware of terrain changes (which can lead to falls). Monitor grill use or lock/cover the grill to prevent use. Encourage fresh air but remember safety!

Other:
- Safety proof the entire home. Think about thermostat locks, plug covers, door locks (ensure doors can be opened from the inside so people don't lock themselves into an area), poisonous plants, hazardous tools, firearms, lighters/matches, etc.
- Vehicles: Bus steps often look like holes & this can make a person afraid to step on them. Improve interior lighting if the person is afraid to get into the car/van (especially on steps). Add color to the edges of steps to define them. Park as close to the curb as possible, especially in taller vehicles, to minimize the height of the last step.
Moving Tips for Individuals with Dementia

Sometimes, an individual with dementia needs to move to a new setting to continue to receive the best quality of care. We know, however, that individuals with dementia do best when their routine and environment remain consistent. Therefore, in an effort to ensure the smoothest transition possible, the following tips were developed.

**Bedroom:**
- Make the new bedroom as similar as possible to the old bedroom. Examples include: arrangement of furniture, color of room, type of décor & bedding, photos, etc. Keep their clothes in the same location at the new home (i.e.: socks in top left drawer).
- Bedding: Solid colors are best. Busy or bold patterns will add to confusion. Ensure the bedding isn’t the same color as the floor/walls to make the bed stand out for the individual.
- Have the individual’s family make a soothing recording of their own voice that can be played for the consumer at their new residence to help ease the transition.
- If the person has certain shows or music they enjoy at home, have these available at the new residence.
- Use familiar scents to assist the transition (i.e.: have family member sleep with a stuffed animal for a while and bring that animal during the move).
- Pictures on wall: place 32” above the floor to ensure the person can see them.
- Lighting: Use overhead lighting if possible. Table lamps create shadow areas that can be frightening to individuals with dementia.
- Remove/avoid throw rugs

**General tips:**
- Visits:
  - The person with dementia may need more trial visits than other individuals.
  - Have familiar staff or family members complete initial visits with the individual.
  - Choose a staff from the new house to be a “preferred staff”. Have that person visit the individual at their present home a few times and then have that staff be present for the consumer’s visits to the residence.
- Assessments: If the individual is moving to a group home or nursing facility, have all necessary assessments (dining, OT, etc.) completed during trial visits so all needs can be addressed and adaptive equipment in place prior to the move.
- Label frequently used/needed items for the individual. Use picture cues on things like dressers or kitchen drawers (showing what is in each drawer), on important rooms (i.e.: bathroom), etc. Using actual pictures of the items is more meaningful for the person than using drawings.
- Avoid glare whenever possible. Look at furniture, floors, walls, etc. Use fabric, flat paint, non-shiny surfaces to minimize glare whenever possible.
- Contrast: Aim to have fixtures be a contrasting color to surrounding areas (i.e.: white toilet in front of colored wall); use a different color molding to separate the wall from the floor; Avoid having floors, walls, furniture, etc. all be similar colors.
- Patterns: Avoid busy patterns on bedding, furniture, carpets/flooring, etc.
Hints for Holiday Visiting


The holiday season is a time for visiting and re-connecting with family, friends and neighbors. Sometimes this season can be sad or stressful for those caring for a loved one with Alzheimer’s disease (AD) or dementia.

- Holidays can be meaningful, enriching times for both the person with AD and family. Maintaining (or adapting) old family rituals and traditions help all family members feel a sense of belonging and family identity. For a person with AD, this link with a familiar past is reassuring and builds self-esteem.
- Set your own limits early, and be clear about them with others. You do not have to live up to the expectations of friends or relatives. Your situation is different now.
- Encourage family and friends to visit EVEN IF IT IS PAINFUL FOR THEM. Keep the number of persons visiting at one time to a minimum, or try a few people visiting quietly with the person with AD in a separate room. Most people with AD can pull it together for brief periods, if they have adequate private rest in between.
- Try some simple holiday preparation with the person with AD several days ahead. Just observing your preparations will familiarize him/her with the upcoming festivities; if they participate with you, they experience the pleasure of helping and giving as well as the fun of anticipation and reminiscing.
- Prepare potential quiet distractions (a family photo album or a simple repetitive chore like cracking nuts) to use if the person with AD becomes upset or over-stimulated.
- Try to avoid situations that further confuse or frustrate many people with AD:
  - Crowds of people who expect the person with AD to remember them
  - Noise, loud conversations or loud music
  - Strange or different surroundings
  - Changes in light intensity – too bright or too dark
  - Over-indulgence in rich or special food or drink (especially alcohol)
  - Change in regular routine and sleep patterns
- Try scheduling activities, especially some outdoor exercise, early in the day to avoid the fatigue from added activity at the end of a long day. Familiar holiday music, story-telling, singing or church services (even on TV) may be especially enjoyable.
- If you receive invitations to holiday celebrations which the person with AD cannot attend, GO YOURSELF. Enjoy the chance to be with friends and family who love you and enjoy your company, with or without your relative.
Preparing the Guests
1. Explain as clearly as possible what has happened to the person with AD. Give examples of the unusual behaviors that may take place: incontinence, eating food with fingers, wandering, hallucinations.
2. Explain that it may not be appropriate behavior but the person with AD has a memory loss and does not remember what is expected and acceptable.
3. Remind the visitor through phone calls or letters to be understanding and not to shun the person with AD.
4. If this is the first visit since the person with AD became severely impaired, tell the visitor the visit may be painful. The memory-impaired person may not remember the guest’s name or relationship.
5. Explain that memory loss is the result of the disease and it is not intentional.
6. Stress with the guests that what is important is the meaningfulness of the moment spent together and not what the person remembers.

Preparing the Memory-Impaired Person
1. Begin showing a picture of the guest to the person a week before the arrival.
2. Spend more time each day explaining who the visitor is while showing the picture.
3. Arrange a phone call for the person with AD and the visitor. The conversation may help both. The call gives the visitor an idea what to expect and gives the memory-impaired person an opportunity to familiarize him/herself with the visitor.
4. Keep the memory-impaired person’s routine as close to normal as possible.
5. During the hustle and bustle of the holiday season, guard against fatigue and find time for adequate rest.
Take Care of Yourself!!

Being a caregiver to an individual with dementia can be a challenging and stressful task. It is imperative that you take care of yourself, if you hope to continue to care for your loved one.

When you are stressed in the moment (while dealing with your loved one):
- Take a deep breath and/or use other relaxation techniques.
- Rephrase or simplify the requested task to help them understand.
- Try to change the subject (get their mind off what may be upsetting).
- Walk away and try again later (as long as it is safe to do so).

Symptoms of Caregiver Stress
- Denial (of disease severity; of caregiver’s stress; etc.)
- Anger
- Social withdrawal (no longer see friends or do things without their loved one)
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of Concentration
- Health Problems

Care for YOURSELF!!
- Understand your limitations. You can’t do/be everything.
- Control/change what you can but don’t try to control everything.
- Accept change as it comes – Be Flexible!
- Stay Physically Active and try to eat healthy.
- Use Relaxation Techniques.
- Try to get time for yourself to recharge.
- Use available family and community resources for help, guidance and support.
- Become educated about the conditions affecting your loved one.
- Give yourself credit, not guilt.
- Join a support group with other caregivers.

Prepare for the Future:
- Get important paperwork completed as a Health Care Proxy or Power of Attorney before a crisis can significantly decrease the caregiver’s stress.
  - Health Care Proxy
  - Power of Attorney
  - Funeral preparation (some individuals may want to help plan their funeral. Final arrangements can also be paid for in advance, if appropriate).
- Gather any insurance, medical and financial information in a safe and easily accessible location.
- Ask the individual about their wishes for the future while they are still able to contribute.