
“At Home With Dementia Care”
Missouri Alliance for Home Care DVD handouts

Approximately 70% of people with dementia or cognitive impairment are living at home. To better respond to their needs, the Missouri Alliance for Home Care and the Alzheimer’s Association have teamed up to create an evidence-based dementia care guide for professionals working in the home setting. The contents of this handout are a culmination of relevant topics assembled from the Alzheimer’s Association’s Dementia Care Practice Recommendations for Professionals training manual. It offers best practice recommendations for professionals providing care in a home setting. The recommendations represent the latest research as well as the experience of care experts. For information on receiving the full version of this manual please contact: The Alzheimer’s Association at 1-800- 272-3900.

Handouts are coordinated with the five modules of the “At Home with Dementia Care” DVD. The topics in focus include: Overview (Module A), Communication (Module B), Behaviors (Module C), Activities of Daily Living (Module D), and Working with Families (Module E).

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MODULE A: Dementia Overview:

Dementia is a category of progressive diseases and disorders that cause deterioration of the brain.

There are over 60 irreversible dementias and a number of reversible dementias, including infections (UTI, pneumonia, medication side effects, depression, etc.). It is important to rule out all of the reversible dementias before a diagnosis of an irreversible dementia can be made.

Alzheimer’s Disease is the most common of the dementias, making up over 60% of all the dementias. Currently there are about 5.4 million people who have this disease and it is expected to climb to over 16 million by 2050. **Fifty percent (50%) of all people at the age of 85 will have this disease. It is the 6th leading cause of death and the only one that has no treatment or cure.**

Alzheimer’s disease is very complex, typically has a slow moving progression, and eventually causes a person to lose the ability to perform daily self-care. All areas of daily living are affected over the course of the disease. Over time, a person with dementia loses the ability to learn new information, make decisions, and plan the future. Communication with other people becomes difficult. People with dementia ultimately lose the ability to perform daily tasks and to recognize the world around them. The range of lifespan for someone with dementia can range from 2-20 years.

In the beginning of the disease, the person may be aware of some changes in memory and rely more on others for reminders. As dementia worsens, the person may get lost easily and be unable to drive or manage finances. In advanced dementia, the person will lose the ability to eat, drink, bathe, dress, or use the toilet without assistance. **Eventually, the people with the disease will be totally dependent on others for help with every daily activity.**

Each person with dementia has a unique set of abilities and care needs that change over time, as the disease gets worse. Yet even when the disease is most severe, **the person can experience joy, comfort, and meaning of life.** The **quality of life depends on the quality of relationships** people with dementia have with their loved ones, their community, and their home care providers. **Build rapport by learning about the person's life story and favorite memories. This information is invaluable in connecting on a deeper level with the individuals for whom you care.** You may need to connect with their loved ones to find out details about their life story (*Life Story questionnaire included in handouts*).

Studies have shown that the early signs of dementia are subtle. They can be mistaken for typical age-related changes and easily missed by patients, caregivers, and even physicians. **People who spend time consistently with the individual in question are often the first to see these signs.** Direct care partners need training not only to recognize these signs and determine what is “normal aging” and what is considered to be abnormal, but also to understand when and how to communicate changes to supervisors, discuss observations with the home care team, or consult with an external expert. **Family caregivers who witness signs of dementia should be referred to a physician or other qualified practitioners.**

The Alzheimer's Association has developed the following “**Ten Warning Signs**”:

- 1) Memory changes that disrupt daily life.
- 2) Challenges in planning or solving problems.
- 3) Difficulty completing familiar tasks at home, at work or at leisure
- 4) Confusion with time and place
- 5) Trouble with understanding visual images or spatial relationships.
- 6) New problems with words in speaking or writing.
- 7) Misplacing things and losing the ability to retrace steps.
- 8) Decreased or poor judgment.
- 9) Withdrawal from work or social activities
- 10) Changes in mood and personality

The following are considered the most common irreversible dementias:

- Alzheimer's Disease – most common type of dementia (approximately 60%)
- Vascular Dementia (includes strokes and TIA's)
- Frontal-Temporal Lobe Dementia (Includes Pick's Disease)
- Lewy Body Dementia
- Parkinson's Disease with Dementia

The following are some causes of reversible dementia:

- Medication side effects/poly pharmacy (too many medications)
- Depression
- Infections (including UTI , pneumonia, fever)
- Malnutrition, dehydration and vitamin B12 deficiency
- Thyroid and metabolic problems

For more information on dementia training including The Alzheimer's Association 'essentiALZ' certification program, please visit www.alz.org or call 1-800-272-3900.

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factsheet

MARCH 2011

alz.org

2011 Alzheimer's Disease Facts and Figures

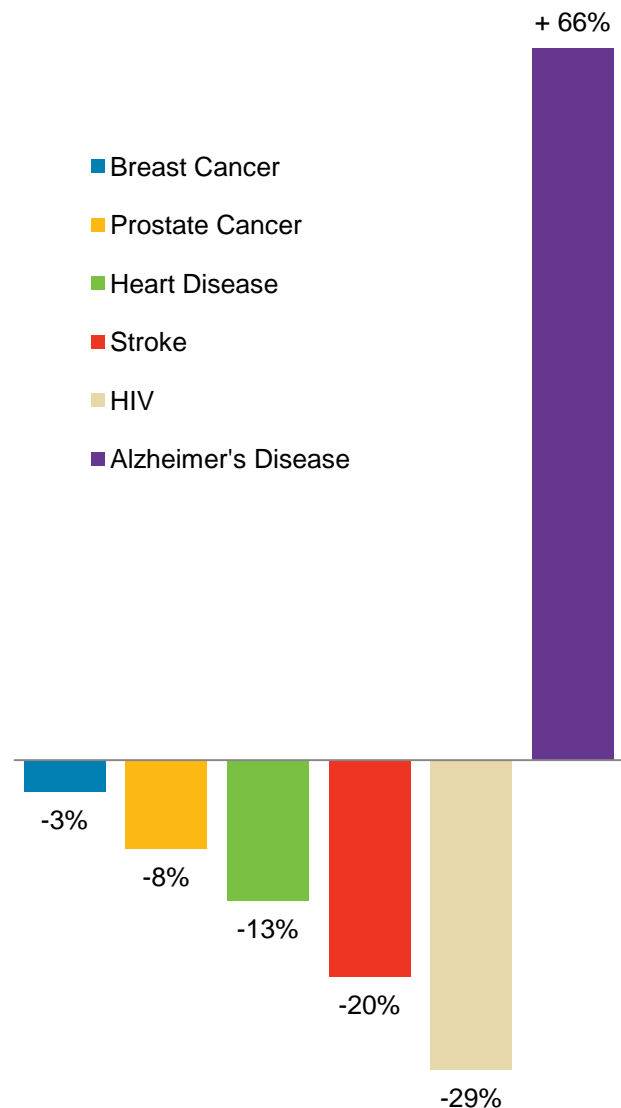
With Alzheimer's, it is not just those with the disease who suffer. It's also their caregivers.

- In 2010, 14.9 million family and friends provided 17 billion hours of unpaid care to those with Alzheimer's and other dementias.
- The economic value of the unpaid care provided to those with Alzheimer's and other dementias totaled \$202.6 billion in 2010.
- More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; one-third report symptoms of depression.

Alzheimer's is not just memory loss. Alzheimer's kills.

- Alzheimer's disease is the 6th leading cause of death in the United States and the 5th leading cause of death for those aged 65 and older.
- Alzheimer's is the only cause of death among the top 10 in America without a way to prevent, cure, or even slow its progression.
- Deaths from Alzheimer's increased 66 percent between 2000 and 2008, while deaths from other major diseases, including the number one cause of death (heart disease), decreased.

Change in Number of Deaths Between 2000 and 2008



Based on preliminary 2008 mortality data

The number of Americans with this devastating and heartbreaking disease is growing – and fast.

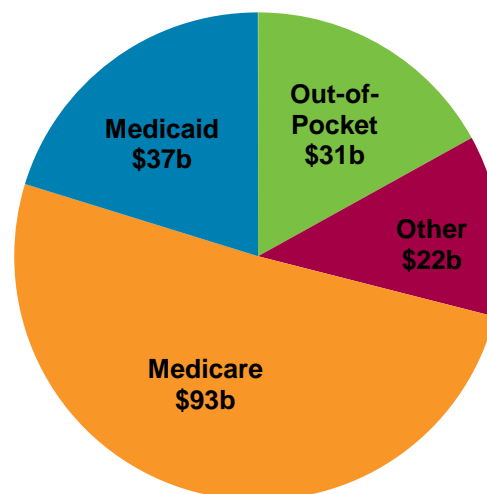
- Today, 5.4 million Americans are living with Alzheimer's disease – 5.2 million aged 65 and over; 200,000 with younger-onset Alzheimer's. By 2050, as many as 16 million Americans will have the disease.
- Two-thirds of those with the disease – 3.4 million – are women.
- Of Americans aged 65 and over, 1 in 8 has Alzheimer's, and nearly half of people aged 85 and older have the disease.
- Another American develops Alzheimer's disease every 69 seconds. In 2050, an American will develop the disease every 33 seconds.
- Most people survive an average of four to eight years after an Alzheimer's diagnosis, but some live as long as 20 years with the disease.
- On average, 40 percent of a person's years with Alzheimer's are spent in the most severe stage of the disease – longer than any other stage.
- Four percent of the general population will be admitted to a nursing home by age 80. But, for people with Alzheimer's, 75 percent will be admitted to a nursing home by age 80.

Facts in Your State

The *2011 Alzheimer's Disease Facts and Figures* report also contains data on the impact of the disease in every state across the nation.

Find the full report and information on your state at www.alz.org/facts

2011 Cost of Alzheimer's = \$183 Billion



Alzheimer's disease has profound implications for government budgets.

- In 2011, the cost of caring for those with Alzheimer's to American society will total an estimated \$183 billion. This is an \$11 billion increase over last year – a rate of increase more than four times inflation.
- Average per person Medicare payments for those with Alzheimer's and other dementias are three times higher than for those without these conditions. Medicaid spending on seniors with Alzheimer's and other dementias is nine times higher.
- Unless something is done, the costs of Alzheimer's to Americans in 2050 will total \$1.1 trillion (in today's dollars).
- Between now and 2050, Medicare spending on those with Alzheimer's will increase nearly 600 percent, and Medicaid spending will increase nearly 400 percent.

KNOW the **10** SIGNS

Early Detection Matters

Have you noticed any of these signs?

Please list any concerns you have and take this sheet with you to the doctor.

Note: This list is for information only and not a substitute for a consultation with a qualified professional.

___1. **Memory changes that disrupt daily life.** One of the most common signs of Alzheimer's, especially in early stages, is forgetting recently learned information over and over, relying on memory aides (e.g. reminder notes or electronic devices) or family members for things they used to handle on their own. What's typical? Sometimes forgetting names or appointments, but remembering them later.

___2. **Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. What's typical? Making occasional errors when balancing a checkbook.

___3. **Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. What's typical? Occasionally needing help to use the settings on a microwave or to record a television show.

___4. **Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. What's typical? Getting confused about the day of the week but figuring it out later.

___5. **Trouble understanding visual images and spatial relationships.** For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. What is typical? Vision changes related to cataracts.

___6. **New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining in conversation. They may stop in the middle of conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary; have problems finding the right word or call things by the wrong name (e.g. calling a "watch" a "hand-clock"). What is typical? Sometimes having trouble finding the right word.

___7. **Misplacing things and losing the ability to retrace steps.** A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. What's typical? Misplacing things from time to time, such as a pair of glasses or the remote control.

___8. **Decreased or poor judgment.** People with Alzheimer's may experience changes in judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. What's typical? Making a bad decision once in a while.

___9. **Withdrawal from work or social activities.** A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. What's typical? Sometimes feeling weary of work, family and social obligations.

___10. **Changes in mood and personality.** The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. What's typical? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have any questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunity for treatment, support and future planning.

For more information, go to www.alz.org/10signs or call 1-800-272-3900

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Module B: Communication:

To ensure that home care is person-centered and aligned with an individual's choices, there must be **good communication** among the individual living with the disease, his or her health care decision-maker, family caregivers and **entire care team**. Cultural perspectives on functioning and disability may vary a great deal. **To be effective, providers must understand the communication challenges presented by those living with dementia.** They must also consider, what, how, and when information should be delivered to family and other team members.

Consider the following communication techniques when communicating with a person who has dementia:

- Introduce yourself by name
- Address the person by the name he or she prefers
- Approach the person from the front before speaking
- Speak to the person at eye level
- Speak slowly and calmly, and use short, simple words/sentences
- Allow enough time for the person to respond (counting to five between phrases is helpful)
- Focus on the person's feelings, not the facts- do NOT argue or try to correct if the information you are sharing causes any anxiety
- Use a comforting tone of voice
- Treat the person as an adult
- Be patient, flexible and understanding
- Avoid interrupting people with dementia; they may lose their train of thought
- Allow individuals with dementia to interrupt you, or they may forget what they want to say
- Recognize people do have something important to say, even if the words don't make sense to you

- Limit distractions during communication (e.g. turn off the radio/tv or move to a quiet place)
- Increase the use of gestures and other non-verbal communication techniques
- Observe the individual to recognize non-verbal communication
- Be aware of body language – yours and theirs
- Ask for assistance/help, rather than give orders
- Remember that an individual has limited ability to understand directions and may forget them

Effective Communication Strategies:

- Use the “TALK” method for communication:
 - Take it slow – speak as slowly and calmly as you can.
 - Ask simple questions – single questions with one-word answers are most likely to be understood.
 - Limit “reality checks” – reasoning may not work.
 - Keep eye contact – non-verbal tactics, such as posture and eye contact, are key to successful communication.

Some general guidelines for working with individuals with dementia who live alone include:

- Always introduce yourself and mention the name of a family member or friend to help the person understand why you are there. If possible, arrange for a family member, friend or home care provider with whom the individual has a relationship to introduce you to the person the first time you visit.
- Allow sufficient time to build trust. Be prepared to participate in friendly conversation while the person gets more comfortable with you.
- If the person will not open the door, sometimes leaving and attempting to visit again later the same day (or another day) is an effective approach.

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Dos and Don'ts To Enhance Communication

Do:

- Listen carefully
- Help a person fill in the blanks
- Read facial expressions and body language
- Give compliments
- Ask opinions
- Ask open-ended questions
- Give generous praise
- Take the blame, apologize
- Be sincere
- Use person's Life Story often
- Rely on humor
- Keep language simple

Some Helpful Phrases

Greetings:

- "I've come to see how you are."
- "I'm so glad to see you!"
- "Hello! It is great to see you again!"
- "I came to visit you, I hope this is a good time?"
- "Seeing your face brightens my day!"

Compliments:

- "You look great in that color!"
- "I really enjoy talking with you."
- "Great job!"
- "Would it be okay if I came to visit again?"
- "Thank you for your help."

Do not:

- Argue, confront, correct
- Give orders, make demands
- Talk down to a person
- Talk about a person in their presence
- Ask in-depth questions
- Try to explain too far in advance
- Take negative comments personally
- Give too many choices
- Try to rush the conversation
- Be insincere, asking questions when you are, in fact, not offering a choice

Some Helpful Phrases

Encouragement:

- "I'd like to invite you to..."
- "And while I'm here, may I help you?"
- "Could you give me a hand with..."
- "I would enjoy it more if you kept me company."
- "Could we do this together?"

Magic Phrases:

- "I need your advice..."
- "I need your help..."
- "I'm sorry."
- "I was wondering..."
- "What do you think?"
- "It would mean a lot if you would let me help."

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Module C: Behavior:

All behaviors, including reactions to daily care, are a form of communication. Behaviors have meaning and indicate an unmet need or desire. The direct care provider is responsible for interpreting and responding to the behavior to determine what the need may be. For example:

- A person repeatedly refusing certain food or beverage may mean he or she does not like it. Simply changing the item may eliminate this behavior. If it persists, it is possible that the person has pain because of a toothache or trouble swallowing. This may require a feeding/swallowing evaluation.
- A person who resists getting dressed may be in pain due to arthritis. Controlling for pain and/or minimizing physical movements that cause pain can address this behavior. Or, maybe the person doesn't like the clothing that has been chosen for him/her to wear. Have the person involved in the choices of clothing.
- A person who resists a bath may feel under attack when someone tries to help take off clothes. Giving the person a view of the tub, starting the bath water before undressing, and keeping the bathroom warm can promote participation in undressing. Use distraction, like singing/dancing to a favorite song while walking to the bathroom

Care Goals:

- A person showing behavioral symptoms needs a thorough medical evaluation especially when symptoms come on suddenly. If an examination is not performed and the symptoms are treated with drugs, the medication could not only mask the symptom but also create a more dangerous situation. Medication should be the last resort in addressing behaviors.
Example: A person exhibiting distressed behaviors may actually have an underlying urinary tract infection that should be treated with antibiotics. The use of psychotropic medication in this case would mask behaviors and leave the underlying cause untreated.

- When working with behaviors, care providers should always use gentle caregiving techniques, including: warnings before touching the person or beginning care, apologies for causing distress, and keeping the person covered and warm.
- Listen to and validate the person’s concerns, address those concerns, and provide reassurance.
- Providers need to determine the causes, or “triggers”, for a person’s behavioral symptoms.
- If a trigger can be identified, every effort should be made to change the situation in order to minimize the behavior.
- If no trigger is identified, distracting the person with dementia by changing the task, the environment, or the topic of conversation may be helpful. **Note: Triggers may include difficulty seeing or hearing, hunger, thirst, pain, lack of social interaction or poor care.**
- Behavioral symptoms can have non-medical causes or could be related to care methods. Care providers can assess various aspects to determine unmet needs:
 - **Physical:** pain, fatigue, constipation, hunger/thirst, cold/hot, chronic conditions (arthritis, etc).
 - **Emotional:** fear of unknown, fear of touch, grief, loss of control, territory, protection, unable to perform tasks, misinterpreting others, not being allowed to make choices, change in routine or lifestyle.
 - **Environment:** noise, too much sound, light, odor, confusing cues, over or under stimulation, clutter, stressful surroundings, boredom, isolation, changes/misunderstanding in layout of home (furniture placement, patterns on wall or floor, etc), change in typical caregivers or houseguests, request to bathe at a different time of day.
 - **Social:** approached too quickly, overly demanding caregivers, unclear communication, unwanted touch, looking for someone or something, need to feel control.
 - **Task:** too difficult, doesn’t understand what is asked, embarrassed, feeling rushed or inability to keep up with task.
 - **Communication:** misunderstanding directions, feeling belittled, disrespected, or treated like a child (“Elder Speak”), body language of caregivers saying, “I don’t care” or “hurry-up”.
 - **Time of Day:** late afternoon is most the common time for individuals to exhibit behaviors, for a variety of reasons.

WANDERING:

Dementia Considerations:

Wandering describes the behavior of people with dementia who move about in ways that may appear pointless but often have purpose. **Wandering, like all behavioral symptoms of dementia, happens for understandable reasons.** It may occur as a result of an unmet need for social interaction or friendship, a noisy environment, pain or distress, boredom or other causes. The urge to wander away from home may be from a desire to return to a former home or workplace. The person may be following old habits, such as leaving for work in the morning. A sunny day, a desire for fresh air, or a daily walk may draw the person outside. **(Note: some people may not actually be trying to leave; they may simply see a door and decide to go through it). Wandering is not necessarily a behavior that must be stopped. Movement can be beneficial.**

Care Goals:

- Collect information about the person's wandering patterns and ways the family prevents unsafe wandering or leaving home. Find out how family members support safe wandering.
- Wandering may happen because of many things that the person with dementia cannot express, including:
 - Physical or emotional needs:**
 - A need for food, fluids, exercise or the toilet
 - Pain, a need to urinate, constipation, infections or medication effect
 - A need for security or friendship
 - Depression, anxiety, delusions or hallucinations, boredom or isolation
 - Environmental irritants:**
 - Too much sound or strange surroundings
 - Changes in routines or caregivers
 - Desire for more physical stimulation:**
 - Desire for fresh air, to see and touch plants, to feel sunlight, or simply to move

- Consider the following ways to reduce the risk of the person leaving home alone:
 - Make doors less obvious so the person who wanders does not realize that leaving home is possible
 - Install a silent alarm system that operates when the person is leaving home
- Consider enrolling the person in Medic Alert + Alzheimer's Association Safe Return. This program is a nationwide system that helps identify, locate and return people with dementia to their homes by mobilizing first responders, communicating with caregivers, and assuring availability of personal medical information, when needed.

PAIN MANAGEMENT:

Dementia Considerations:

Pain is common in persons with dementia, just as it is in other older adults. Pain is any unpleasant physical, emotional, social or spiritual experience. It can have a quick onset or persist over time. Many people with dementia may not volunteer information about pain, but, when asked, they can often verbalize the experience, particularly when the affected area is moved or examined. **People with dementia often have trouble expressing pain making it difficult to assess pain and discuss approaches to treatment.** People with dementia communicate pain in different ways – verbally and nonverbally. **As verbal ability declines, people with dementia rely more on non-verbal communication. This can include behavioral symptoms of resistance to care.** These symptoms can lead to the inappropriate use of psychotropic medications.

Care Goals:

- Prevention of pain is the first defense against it.
- Pain *may* be prevented through the regular or scheduled use of medications to relieve pain.
- Other possible ways to ease pain that do not include medications include: relaxation, physical activity, massage therapy, distraction, superficial heating or cooling (such as heating pads or ice packs), the use of assistive devices such as a cane, and repositioning (moving the person so that he or she is more comfortable).

- For people with dementia who cannot answer questions about discomfort or pain, all home care providers must watch for signs of pain that may indicate the person is experiencing pain.
- Observing people during self-care may indicate some movements are painful. Indications could include: slow movement, holding and/or frequently touching an extremity, or favoring an extremity or other body part.
- Pain may be the cause of behavioral symptoms, such as restlessness, grimacing, or crying out or groaning.
- When pain occurs and the cause is not known, assess the person's condition. Ask family about the person's past pain experiences and document the responses.

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Module D: Activities of Daily Living (ADL's):

Dementia Considerations:

People with dementia are less able to take care of themselves as the disease progresses. At first, a person may need only prompting or a little help, but **eventually caregivers will become responsible for all personal care. The loss of independence, control and privacy can be unpleasant or threatening for the person with dementia.**

Care Goals:

- Provide care that is sensitive to the person's abilities, and maximizes independence and participation in personal care.
- Provide care that takes into account cultural sensitivities around such issues as communication, care delivery, and care choices.
- Anticipate changes and plan ahead to provide care that is based on knowledge of the individual's choices, needs, and abilities.
- Be flexible with both the person with dementia and the family caregiver – adapt to the person's choices.
- Promote independence by helping a person to do as much as possible by himself or herself.
- Guide the person through tasks by using easy, step-by-step directions. Praise or acknowledge the person for each step completed.
- Use an empowerment approach to return control to the person and make them aware of care activities.
- Tell the person what you are doing and get their permission to do it. For example, say “I'm going to wash your back now, is that okay?”
- Speak in short, simple words, and remember the importance of cultural sensitivity and context.
- Avoid rushing the person through a task.

- Watch for unspoken communication. **Example: a person may express discomfort through behaviors such as wincing, yelling or striking out.**
- Try new approaches to care if the one in use does not work.
Example: If the person wants to put on his shirt after his shoes and socks, go along and provide assistance.

BATHING:

Dementia Considerations:

Bathing can be a frightening experience for a person who may not understand what is happening or be uncomfortable or unfamiliar with the environment. **The person with dementia may forget how to bathe, be cold, or think the family caregiver or direct care provider is trying to assault him or her.** As a result, the person with dementia may resist care.

Care Goals:

- Promote safety at all times. Recognize the point at which it is no longer safe to leave the person alone, and *never* leave the person alone in the bathroom.
- Help the person feel in control by involving and coaching the person through each step of bathing at the appropriate level. **Example: Include the person in the process by asking him or her to hold the washcloth or shampoo bottle. Avoid asking the person to do a task that is too difficult.**
- Ask what time of day and what routine is best for bathing given the person's choices and previous routines.
- Consider whether a person may be afraid of water or have a depth perception impairment that may make entering a bathtub frightening.
- Respect the person's dignity by providing a towel to cover his or her body throughout the process.
- Washing the person's hair may be the most difficult task. Use a washcloth to soap and rinse hair in the sink to reduce the amount of water on the person's face.
- Recommend installing grab bars on the wall and tub edge. Place non-slip mats on the floor. Use a tub bench or bath chair that can adjust to different heights.

ORAL CARE:

Dementia Considerations:

Proper care of the mouth and teeth can help prevent eating difficulties, pain and digestive problems. Brushing is sometimes difficult because a person with dementia may forget how or why it is important. Correct care is more than just good hygiene; it is essential to overall health. Poor oral care increases the risk of respiratory infection or pneumonia.

Care Goals:

- Provide short, simple instructions, and break down each step such as: 1). Hold your toothbrush 2). Put paste on the brush and 3). Put the brush in your mouth.
- Investigate any signs of discomfort while eating, such as strained facial expressions or grimacing; these may indicate pain.
- Monitor for any swallowing difficulty (e.g. repeated coughing or throat clearing) and modify the task of brushing accordingly.
- For individuals with advanced dementia, consider using a “toothette” (a cushioned swab for the mouth) or other tool to clean the mouth and gums.

Note: if the person clamps down their teeth and jaw during dental care, do not try to force the toothette or toothbrush out of his or her mouth; wait patiently for the jaw to be released

DRESSING:

Dementia Considerations:

Respect the person’s dressing style. Some people like to be well dressed at all times and consider it a source of pride. Others do not feel dressing up is important and this choice should be equally respected. Attempt to gather this information from family if the person with dementia is unable to communicate.

Care Goals:

- Simplify clothing choices for the person according to his or her ability to choose.
- Organize the process by laying out clothing items in the order that they will be used.
- Give the person short, simple instructions while handing them an item such as “Put on your shirt”. Sometimes just handing the person an item of clothing (without saying anything) will facilitate dressing.

- Choose comfortable, simple clothing that is easy to put on and take off. Consider cardigans, or other clothing that buttons in the front, rather than pullovers. Substitute zippers or Velcro for buttons. Keep in mind that if you alter a familiar routine or method, the person with dementia may have difficulty learning something new, so try to follow the same routine and use familiar fasteners for as long as possible.
- Ensure the person has enough time to dress before leaving the house. Avoid having to rush.
- If the person resists dressing, stop the process and try again later. Sometimes it is less troublesome to have people sleep in their clothes and help them change in the morning.

TOILETING:

Dementia Considerations:

People with dementia may have accidents because they may not know where the toilet is, recognize the toilet, or realize they have to use the toilet until it is too late. **Many people in the later stages of dementia lose control of their bladder and/or inability to recognize natural urges, forgetting where the bathroom is, or medical issues such as a urinary tract infection or side effects from medicine.** Have a doctor evaluate potential causes of incontinence.

Care Goals:

- Determine the person's typical urinary and bowel patterns by talking with family caregivers. Find out how they help the person use the toilet. Based on this information, create a toileting schedule and methods for managing a person's needs.
- Be supportive by helping the person retain a sense of dignity. Reassure the person to reduce feelings of embarrassment.
- Install a nightlight in the room to guide the way to the bathroom.
- Create visible reminders. Post a sign or picture of a toilet or make the toilet more visible.
- Limit fluid intake at night prior to bedtime.

EATING AND DRINKING:

Dementia Considerations:

Dementia may lead to changes in eating or drinking (e.g. eating more or less) because those affected by it may not be able to prepare meals, remember to eat or drink,

remember when they last ate, know or be able to say that they are hungry or thirsty, or smell and taste in the same way they did before. Steps should be taken to enhance taste and encourage appropriate food intake. Using utensils such as knives, forks, spoons, dishes and cups may be difficult or impossible in the later stages of eating, but if a spoon is placed in their hand, he or she may begin to eat. **It may become more difficult for the person with dementia to swallow foods and liquids safely as dementia progresses (e.g. individuals may not swallow food or liquid in their mouth because they no longer sense it or they forget to swallow).** They may be at a higher risk of aspiration (inhaling food and/or liquids into the lungs). A person with dementia may have difficulty recognizing food or liquid, even when it is in his or her mouth. Family caregivers are often heavily involved in food choices, cooking, and helping the person with dementia eat or drink. **It is often difficult for them to accept that the person with dementia may not be able to eat or lacks interest in certain foods or liquids.**

Care Goals:

- Help to make mealtime pleasant and enjoyable; involve family when the person and family are amenable.
- If possible, discuss with the person's caregiver the eating or drinking habits, the preferred foods, and successful ways in which the family caregivers help the person eat or drink.
- Keep the person's familiar eating and dining routines as long as they are practical and promote eating and drinking.
- Promote snacking throughout the day. A formal meal is not needed to assure sufficient food and fluid intake.
- During the meal, people often need help with eating and drinking, but they should be encouraged to do as much as they can on their own to continue to be as independent as possible.
- Increase color contrast between food and plate, and plate and table to promote eating.
- Adjusting the size, shape, and texture of food may help the person eat.
- Some people will eat and drink better if they have fewer choices. Serving one food at a time can help.
- If finger foods are necessary, try physically guiding the person's hand to the food as a way to facilitate involvement in the activity.
- It is ideal for direct care providers to sit, make eye contact, and speak with people when helping them with meals.
- People in the end stages of dementia may lose weight due to lack of interest in food or beverages, the disease process, or an inability to eat or drink. They may need only comfort care, or may still eat or drink simply for pleasure when capable.

FALLS:

Dementia Considerations:

People with dementia have a greater risk of falling because they can have problems seeing, thinking, moving, and balancing. Personal risks for falls include: history of falls, depression, visual problems, muscle weakness, fear of falling, multiple medications, being tired, blood pressure problems, incontinence, and being unable to move or having difficulty with movement. Dehydration puts a person at risk for falls, especially during changes of position such as getting out of a bed or chair. Use of certain drugs may increase falls by causing fatigue or confusion, visual impairment, or dizziness.

Note: sleep medications, anti-anxiety medications, pain medications and narcotics, blood pressure medications, antihistamines, and diabetic medications are among the types of drugs most likely to cause falls.

Care Goals:

- Encourage daily exercise to increase or maintain physical strength.
- Minimize fall-related injuries by avoiding physical restraints, such as a chair that a person cannot leave.
- Have a regular exercise or walking program, for those people who can safely take part, to maintain or improve function, posture, and balance.

Environment risks for falls include:

- Confusing environment and clutter
- Slippery footwear
- Unsafe equipment
- Lack of stable furniture or handrails
- Surfaces that are uneven, slippery or have a glare
- Poor lighting, especially at night
- Rugs and doormats

For more information on dementia training including The Alzheimer's Association 'essentiALZ' certification program, please visit www.alz.org or call 1-800-272-3900.

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“At Home With Dementia Care”
Missouri Alliance for Home Care DVD handouts

Module E: Working With Families:

Dementia Considerations:

Family members play a vital role in helping a person with dementia remain at home. They provide a variety of support services and may be trained by the home care team to deliver skilled services such as changing sterile wound dressing or performing diabetes care. **Family caregivers must be vigilant 24 hours a day, to make sure that the person with dementia is safe and well. This constant, complicated caregiving takes a toll on family caregivers.** Family members and other unpaid caregivers are more likely than non-caregivers to report that their health is fair to poor.

Providers must be aware and respectful of a family’s culture. A family’s decision to use support services – and the types of services they use – may be influenced by its culture or by barriers to care, such as limited English proficiency or a lack of support services in the community.

Communication should continue as dementia gets worse so that everyone understands how a person’s needs are changing and what these changes mean to care.

Care Goals:

Consider the following techniques when communicating with families:

- Make information clear and easy to understand
- Consider the family’s level of health literacy
- Reduce the amount of medical jargon and explain any unfamiliar terms
- Use visual aids and demonstration when appropriate
- Clearly explain dosages and when medications should be given
- When appropriate, provide printed information in the family’s preferred language, and use interpreters if necessary.

- Check for comprehension by having the person with dementia and the family caregiver repeat instructions in their own words.
- Hold routine home care meetings

Home Care Meetings: routine home care discussions with caregivers may include the following topics

- Changes anticipated as the disease progresses – what to look for, when to contact a doctor, information on delirium and ongoing monitoring
- Care goals and possible adjustments over time
- Preparing for loss of decision-making capacity
- Wandering risks and precautions
- Actions that place patient or family at risk of harm
- Altered sleep/wake cycle
- Incontinence
- Recognizing and managing pain
- Risks of falls
- Alternatives to restraints
- Diet and meals; signs of swallowing difficulty
- Preparation of foods the person can eat safely
- Caregiver stress and use of respite
- Safety issues such as driving a car

Tips for Provider Self-Care:

- Get proper rest.
- Use your team for support. Regular communication with your supervisor or colleagues in your field can be beneficial.
- Be aware of the physical and emotional impact of providing home care to individuals and families affected by dementia. Talking with someone you trust, or writing about your experiences, can help relieve stress.
- Regularly affirm your successes in enhancing each person’s quality of life, and recognize that “success” often needs to be redefined as client’s condition progresses.
- Honor your grief when the person’s condition changes or the person dies.

- Prioritize participating in activities that you enjoy.
- Nurture a sense of humor. Laughter heals the body and mind.
- Set and maintain appropriate boundaries with the individuals and families you serve to avoid creating unrealistic expectations and prevent burnout.
 - Avoid sharing your personal phone number or other contact details (e.g. your personal email address) with the individuals and families to whom you provide care. Most agencies provide information to persons with dementia and family caregivers about how to obtain assistance when they cannot reach members of their care team.
 - Recognize that every time you go beyond your job description to help individuals or families affected by dementia, you create an expectation that you will continue to do so in the future. You also “model” this behavior for members of your team.
- Seek professional help if you find that: your work interferes with your ability to take care of yourself in the ways described above, you are unable to fulfill your personal commitments, or you are emotionally drained on a consistent basis.
- You deserve the same support that the person with dementia and their family caregivers receive. Your ability to continue serving them well depends on your ability to take care of yourself.

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Introduction to Life Story

What is it?

1. A detailed information tool designed to foster relationships between staff, residents, and family members
2. Identifies information to help provide comfort, joy and a better quality of life
3. A way to help make families feel more connected as part of the care team
4. Includes lifetime information categorized by eras:
 - Personal statistics
 - Activities of interest
 - Likes and dislikes, personal preferences
 - Lifestyle patterns and routines
 - Things that comfort; things that upset
 - Personality traits for enjoyment; cues/signs of anxiety, anger, sadness, etc.

Who completes it?

1. Families/significant others (including longtime friends) should complete a life story. **THIS IS NOT A HIPAA DOCUMENT- there is no medical information involved.**
2. Can be done in a phone interview by a volunteer
 - Be creative with how to obtain information
 - Helpful to have before a person starts in the program but can be completed anytime
3. Can be done as a “Getting to Know You” activity

How to use it

- Must be made accessible to all staff - Kept in a commonly accessed area within the house
- Gather information to make first few days of participation special and help with transition
- Will indicate activities of interest throughout the progression of the disease process (as a person’s memory is moving back in time)
- Will help staff understand the basis of some behaviors
- Help provide clues to behavior triggers; ways to alleviate or diminish behaviors
- Help establish life of choice, respect, individualization, and dignity

The Life Story

The LIFE STORY is a documented account of an individual's life. It helps the staff get to know new participants. Typically, the only information that staff receives on a new participant is medical, or information that pertains to physical care. The LIFE STORY is especially helpful to the staff when they are caring for and designing activities for someone new. A relationship is begun with the person when this information is shared. It can feel like they have known each other forever.

The LIFE STORY can take on many forms. It can follow the format included here or be put into a binder with pictures, drawings, captions, etc. It can be a series of slides or a video. The intent is to begin to foster a relationship between professional caregivers and the participants, and families, too.

By using the LIFE STORY we hope to eliminate feelings of isolation and alienation that a new participant may feel. We also hope it will reduce anxiety with potential catastrophic reactions as well as assist in guiding the new individual in finding their niche. Family members and friends are considered partners in care and are encouraged to help complete the life story.

Even though this is written in first person, anyone who is close to the individual can complete it. Please be as thorough as possible and feel free to add your own information and thoughts. **This document is only a guide.** You can adapt it to fit your needs. It is, however, important to maintain the integrity of the intended purpose.

Please don't be discouraged by its length. The more detailed the information, the more valuable it is.

Thank you.

The Life Story

Name

Nickname

Current Age

Birthplace

List and describe places you have lived.

Please describe things you remember about the home you grew up in.

List and describe places you have visited or traveled.

Do you have a favorite place? (Traveled or not)

Please describe your favorite childhood memories.

Who were your childhood friends? What kinds of things did you do together?
(games played, toys, etc)

The Life Story

List by name and describe your siblings.

Describe your parents. What were their names? What did you call them?

Tell us about your schooling.

Did you date? Who was your first love? When was your first kiss?

How/where did you meet your spouse?

What was your wedding like? (Where, gifts, honeymoon)

List by name and describe your children. Are any of them no longer living?

The Life Story

Who were your best friends?

Who are your best friends?

Describe your jobs and work history.

Did you drive? What kind of cars did you have?

Please describe your pets. Did you have a favorite childhood pet? Tell us a story/memory about you and your pet.

What were some of your previous hobbies or recreational activities?

Please tell us about your religion, denomination, worship, etc. Is it important to you?

The Life Story

Describe some of your Holiday celebrations

Favorites

Color

Food

Flower

Animal

Holiday

Person

Item of Clothing

Food

Comfort Food

Book

Movie

Movie Star

Pass Time

Treasured item

Please describe yourself. (Likes, passions, temperament...)

How would other people describe you?

The Life Story

Do you consider yourself a loner or a people person?

What worries/stresses you?

What comforts you when you are stressed?

How do you act when you are upset about something?

Tell us about your Genealogy (nationality, pertinent family history)

What were some turning points/ significant events in your life?

Any additional information you would like to tell us?