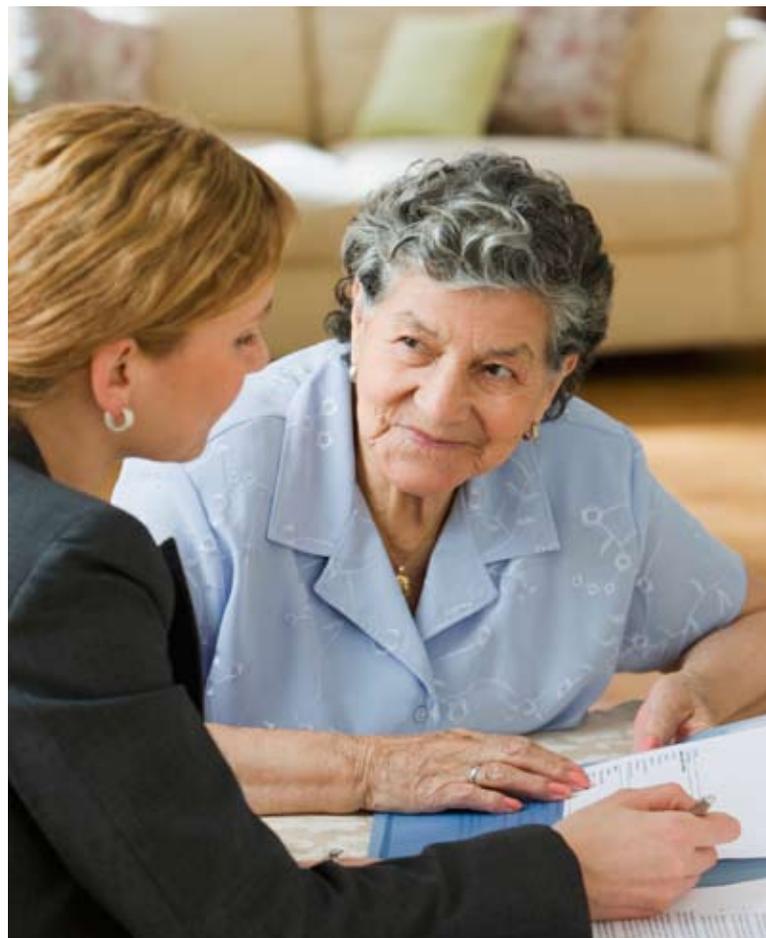


Alzheimer's Association
Campaign for Quality Care

Dementia Care Practice Recommendations for Professionals Working in a Home Setting

Phase 4



Building consensus on
quality care for people
living with dementia

alzheimer's  association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

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The Alzheimer's Association offers quality care education programs for professionals who work in nursing homes, assisted living residences and home settings. For more information, call 1.866.727.1890 or visit www.alz.org/qualitycare.

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Campaign Overview

For more than 25 years, the Alzheimer's Association® has been committed to advancing Alzheimer research and enhancing care, education and support for individuals affected by the disease. Building on our tradition of advocacy for improving the quality of life for people with dementia, we launched the Alzheimer's Association Campaign for Quality Care in 2005.

Approximately 70 percent of people with dementia or cognitive impairment are living at home. To better respond to their needs, we have joined with leaders in dementia care to develop the evidence-based *Dementia Care Practice Recommendations for Professionals Working in a Home Setting*. The home setting recommendations, in addition to those named below, are the foundation of the campaign.

Each year we focus on a different set of care recommendations that can make a significant difference in an individual's quality of life. Our *Phase 1* recommendations focus on the basics of good dementia care, food and fluid consumption, pain management and social engagement. *Phase 2* covers wandering, falls and physical restraints. *Phase 3* covers end-of-life care practices and issues. And *Phase 4* addresses all of these practices as they relate to the home setting.

To date more than 30 leading health and senior care organizations have expressed support and acceptance for one or more phases of the Dementia Care Practice Recommendations. We are grateful to these organizations for their counsel during development of the recommendations and for helping to achieve consensus in our priority care areas.

STRATEGIES FOR QUALITY CARE

All aspects of our Quality Care Campaign — from the selection of priority care practice areas to the development of recommendations, educational programming and advocacy — are based on the best available evidence on effective dementia care. We are using four strategies to achieve the overall campaign goal:

- To encourage adoption of recommended practices in assisted living residences, nursing homes and home settings, we advocate with dementia care providers.
- To ensure incorporation of the practice recommendations into quality assurance systems for nursing homes, assisted living residences and home settings, we work with federal and state policymakers.
- To encourage quality care among providers, we offer training and education programs to all levels of care staff in assisted living residences, nursing homes and home settings.
- To empower people with dementia and family caregivers to make informed decisions, we developed the Alzheimer's Association CareFinder™. This interactive, online tool educates consumers about how to select care providers and services and how to advocate for quality care.

Organizations Supporting the Dementia Care Practice Recommendations, Phase 4

AARP	Gerontological Advanced Practice Nurses Association
American Academy of Home Care Physicians	Hospice and Palliative Nurses Association
American Academy of Hospice and Palliative Medicine	National Association for Home Care and Hospice
American Association of Homes and Services for the Aging	National Association of Social Workers
American Dietetic Association	National Gerontological Nursing Association
American Geriatrics Society	National Hospice and Palliative Care Organization
American Medical Directors Association	National Private Duty Association
American Occupational Therapy Association	PHI
American Physical Therapy Association	American Speech-Language-Hearing Association accepts the recommendations
American Society of Consultant Pharmacists	
Catholic Health Association	
Center for Health Improvement	

We are enlisting the support of these and other organizations, as well as consumers and policy-makers, to help us reach the goal of our Quality Care Campaign — to enhance the quality of life for people with dementia by improving the quality of dementia care in assisted living residences, nursing homes and home settings.

Phase 4



Introduction to Dementia Care Practice Recommendations Phase 4

Edited by Elizabeth Gould, M.S.W., Jane Tilly, Dr. P.H., and Peter Reed, Ph.D.

Dementia Care Practice Recommendations for Professionals Working in a Home Setting is the latest in a series of dementia care practice recommendations offered by the Alzheimer's Association. Three previously published manuals (Phases 1, 2 and 3) provide recommendations for care in nursing homes and assisted living residences.

This manual 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.

Specifically, the Association used the following information to develop its home care practice recommendations:

- A summary of research findings from *Dementia, a NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care*; commissioned by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) and published by The British Psychological Society and Gaskell in 2007.
- The combined knowledge of Alzheimer's Association chapter members, its early stage advisor team, and experts from more than 20 national associations. These individuals worked collaboratively to translate research, knowledge and experience into practical recommendations for those providing care in the home.

Underlying the home care practice recommendations is a person- and family-centered approach to dementia care. This approach involves tailoring care to the abilities and changing needs of each person affected by the disease. It also respects the cultural values and traditions of each family and counts family members as part of the care team.

The recommendations emphasize the importance of personalized care and relationship building. Providers are encouraged to learn about an individual's cultural background, personal history, abilities, and care choices in order to make informed decisions and build rapport. They are also encouraged to build strong relationships with family members who are part of the care team and to understand the family's choices concerning care. Providers who have good dementia training will be most effective in delivering personalized care.

This manual is divided into eight main sections. Following a brief introduction and general description of dementia and its effects, the first section provides an overview of good home care. The *Personal Care Guide* that follows is at the heart of the manual. It defines dementia considerations, care goals and recommended practices related to a broad range of care topics. The recommended practices for each topic include guidelines for assessment, suggested provider approaches and, where applicable, tips for modifying the environment. Additional sections on personal autonomy, home safety and end-of-life care supplement the *Personal Care Guide* using the same approach. Sections on home care provider training, special topics and a glossary of terms complete the manual.

Use of the Terms “Provider” and “Family Caregiver”

There are a variety of paid “providers” who care for people with dementia in their home. Paid home care providers can range from professionals (e.g. nurses and therapists) and paraprofessionals (e.g. personal care aides), to non-medical persons (e.g. homemakers and chore services workers) who deliver services to persons with dementia. These providers may function independently or as members of a care team. For the purpose of these practice recommendations, the focus is primarily on those providers who are part of a team, participate in care planning meetings and provide care determined by a formal care plan(s). In some cases, there is reference to a specific discipline or level of care provider such as direct care provider (including certified nursing assistants, home health aides and personal care assistants), professional practitioner (including nurses, social workers and rehabilitation therapists), or supervisor.

Throughout this document, the term “family caregiver” refers to any family member, partner, friend, or other significant person who provides or manages the care of someone who is ill, disabled or frail. There may be more than one family caregiver involved in a person’s care.

Dementia and Its Effects on the Person with the Disease and Family Caregivers

Dementia is an illness that affects the brain 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.

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, someone who is dying of dementia may not be able to swallow safely, talk, or get out of bed and will be totally dependent on others for help with every daily activity. Throughout the course of the disease, individuals may become sad, agitated, wander or resist care. These behaviors are a form of communication that signifies the person's emotional condition and reactions to care.

Dementia also affects family caregivers. Seventy percent of persons with dementia live in the community, and family caregivers are largely responsible for helping them to remain at home. Family caregivers must be vigilant 24 hours a day to make sure that the person with dementia is safe and well. Their responsibilities include: house-keeping; shopping; managing finances; managing medications; helping with daily activities, such as eating, drinking, bathing, and dressing; ensuring that someone who wanders can do so safely; and overseeing other health care needs which may include conditions like diabetes or heart disease. Providing constant, complicated care to a person with dementia takes a toll on family caregivers. Family members and other unpaid caregivers of people with Alzheimer's and other dementias are more likely than non-caregivers to report that their health is fair or poor. (*Alzheimer's Association 2009 Alzheimer's Disease Facts and Figures*)

1

The Basics of Good Home Care

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 in life. The quality of life depends on the quality of the relationships people with dementia have with their loved ones, their community, and their home care providers.

Ten Warning Signs

Studies have shown that the signs of early dementia are subtle. They can be mistaken for typical age-related changes and easily missed by patients, caregivers, and even physicians. Providers and family caregivers are often the first to see these signs. Direct care providers need training not only to recognize the signs 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. Families can also benefit from education about the warning signs. Family caregivers who witness signs of dementia should be referred to a physician or other qualified practitioner.

The Alzheimer's Association has developed the following "Ten Warning Signs":

1. MEMORY CHANGES THAT DISRUPT DAILY LIFE.

One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aids (e.g. reminder notes or electronic devices) or family members for things they used to handle on their own. **What are typical age-related changes?** 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 are typical age-related changes?** Making occasional errors when balancing a checkbook.

3. DIFFICULTY COMPLETING FAMILIAR TASKS AT HOME, AT WORK OR AT LEISURE.

People with Alzheimer's disease 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 are typical age-related changes?** Occasionally needing help to use the settings on a microwave or record a television show.

4. CONFUSION WITH TIME AND 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 are typical age-related changes?** 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 realize they are the person in the mirror. **What are typical age-related changes?** Vision changes related to cataracts.

- 6. NEW PROBLEMS WITH WORDS IN SPEAKING OR WRITING.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a 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 are typical age-related changes?** 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 are typical age-related changes?** 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 or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What are typical age-related changes?** 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 are typical age-related changes?** 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 are typical age-related changes?

Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Other conditions commonly associated with changes in cognition in older adults, with and without dementia, include delirium and depression. When these conditions are suspected, the person's health care providers should be notified promptly.

- Delirium is an acute, usually reversible, worsening of cognition characterized by inattention and disorganized thinking along with altered levels of consciousness. Caregivers should look for a sudden change in the person's baseline mental status.
- Depression is another common condition that, along with depressed mood or irritability, can be associated with changes in memory. Memory and depressed mood often improve with antidepressant therapy.

Communication with Individuals and Family

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 and his or her health care proxy 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.

CONNECTING WITH INDIVIDUALS

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
- Speak to the person at eye level
- Speak slowly and calmly, and use short, simple words
- Allow enough time for the person to respond (counting to five between phrases is helpful)
- Focus on the person's feelings, not the facts
- Use a comforting tone of voice
- 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
- Limit distractions during communication (e.g. turn off the radio 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

OVERCOMING CHALLENGES

Language, hearing or vision problems as well as low levels of health literacy may present obstacles to effective communication. Providers should take the following issues into account for both individuals and family.

- A person with dementia may sometimes require more time to process information and may take longer to respond to a question.
- Short sentences, visual cues or pictures may help the person with dementia understand what he or she is hearing. Hearing loss is very common in older adults and is often undiagnosed.
- Interpreters may be needed if English is not the primary language or if the person with dementia uses sign language.
- Determine if the person with dementia or the family caregiver has difficulty hearing or seeing. Do they require a hearing aid or eyeglasses? Are those items being used and are they effective?
- Some people may not be "health literate." They may need help to understand some health concepts, terminology, or the implications of treatment options. When health literacy is low, simple verbal explanations may be more effective than written information.

THE LANGUAGE OF BEHAVIOR

All behaviors, including reactions to daily care, are a form of communication. The direct care provider is responsible for interpreting and responding to behaviors. For example:

- A person repeatedly refusing a 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 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.
- A person who seems to misunderstand a lot or does not respond when spoken to may have hearing loss. Proper care and use of hearing aids or other recommended assistive listening technology is important.
- 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.

CONNECTING WITH FAMILY

- Holding regular care planning meetings is important. As dementia progresses, they provide recurring opportunities to create understanding about a person's changing needs and to discuss the implications of those changes on care choices. Families need to know the symptoms of dementia and understand the progression of the disease.
- Every family needs easy access to a home care team that responds to its needs and questions. Schedules vary — providers come and go — so communication can be difficult. Providers must coordinate their work with families and others, including a private care manager the family or insurer hires. Responsive communication can include team meetings that involve family. It can also include assigning a primary nurse or social worker to the person with dementia, and keeping regular contact through home visits, phone calls, or (if available and appropriate) email, text messages or other electronic technologies.

NOTE: Providers should take steps necessary to comply with state and federal law concerning privacy matters.



Involvement of Family and Support Services

Family members may 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 a sterile wound dressing or performing diabetes care. In addition, community-based services providing home-delivered meals, transportation or home modification often play a role. This patchwork of support services requires coordination and communication to be successful.

Family members may need assessment to identify their own needs for education, support and services and reassessment as the person's dementia progresses or the caregiver's health and emotional well-being is impacted. A social worker can refer families to community resources such as the Alzheimer's Association.

Providers must be aware and respectful of each 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 TECHNIQUES

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 discussion 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 for 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

Behaviors

- Most persons with dementia will experience behavioral symptoms. Early on, people may have a hard time concentrating and experience irritability, anxiety or depression. Later in the disease other symptoms may occur, including: sleep disturbances, outbursts, emotional distress, paranoia, delusions (belief in something not real) or hallucinations (seeing, hearing, or feeling things that are not there). These symptoms are hard on people and their caregivers.
- These behaviors and the emotional state of persons with dementia are most often forms of communication because they cannot make their needs known in other ways.

EXAMPLE: A person may resist getting dressed because of joint pain due to arthritis but he or she cannot express this discomfort in words.

BEHAVIORAL SYMPTOMS — CAUSES AND CARE

- A person showing behavioral symptoms needs a thorough medical evaluation especially when symptoms come on suddenly. If an examination is not performed and symptoms are treated with drugs, the medication could not only mask the symptom but also create a much more dangerous situation.

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.

- Behavioral symptoms can also have non-medical causes. These causes include: a change in the person's care, such as admission to a hospital; a change in care provider; the presence of house-guests; or a request to bathe or change clothes at a different time of day. Assessment should also address personal comfort, pain, hunger, thirst, constipation, full bladder/bowel, and fatigue. Loss, boredom and isolation can also cause behavioral symptoms.
- An environmental assessment of the home directed at possible hazards is appropriate. A comfortable, simple, clutter-free environment can reduce behavioral symptoms. Creating a comfortable environment can involve adjusting room temperature, providing supportive seating, eliminating glare, reducing noise levels and offering enjoyable activities (e.g. listening to music or reading). Providers should help families understand the importance of a comfortable home environment.
- If behavioral symptoms are related to care methods, focus on unmet needs.
 - Use gentle caregiving techniques including: warnings before touching a 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 and family need to be able to recognize behavioral symptoms of dementia. Direct care providers need to communicate these symptoms to supervisors or other members of the home care team.

A checklist, like the one below, can help identify behavioral symptoms:

- ✓ Changes in ability to focus (e.g. attention or concentration)
- ✓ Changes in level of alertness
- ✓ Emotional or physical agitation
- ✓ Changes in mood
- ✓ Hallucinations
- ✓ Delusions
- ✓ Suspicion of others
- ✓ Withdrawal from others
- ✓ Groaning or calling out
- ✓ Making faces (e.g. grimacing)
- ✓ Striking out or other signs of distress
- ✓ Wandering
- ✓ Pacing
- ✓ Rocking

- Providers should help determine if a person's behavior is due to a known cause, such as medication effect, the home environment (e.g. noise, clutter), a change in health (e.g. infection, pain or dehydration) or emotional conditions (e.g. depression, boredom), that requires assessment and possible treatment.

- Providers need training to determine the causes, or “triggers,” for a person’s behavioral symptoms.

NOTE: Triggers may include difficulty seeing or hearing, hunger, thirst, pain, lack of social interaction or poor care.

- If a trigger is identified, every effort should be made to change the situation in order to minimize the behavior.
- If no trigger can be identified, distracting the person with dementia by changing the task, the environment, or the topic of conversation may be helpful.
- With appropriate assessment and treatment by members of the health care team, behavioral symptoms can be reduced or stabilized. Success depends on:
 - Identifying the symptoms, their timing and frequency. All members of the care team, including family, can provide information.
 - Using assessment to understand the symptoms’ causes.
 - Treating any medical causes, and changing care or the environment to solve the problem.
 - Monitoring symptoms and changing care as needed.
- Family caregivers and direct care providers need training in behavior management for persons with dementia. They also need access to behavioral experts when behaviors cause distress to the person living with dementia.

USE OF MEDICATIONS

- If non-pharmacological approaches are not effective, medication may be helpful for those with severe behavioral symptoms or those who may harm themselves or others.

- Medications can be effective in some situations, but they must be used carefully. Medications are most effective when combined with non-pharmacological approaches. It is important to evaluate a medication’s effect on a person’s health, mental function, comfort, risk of falls, changes in appetite, dizziness and quality of life.
- If a person uses medications, physicians (in consultation with members of the home care team) need to consider how they will be given:
 - Can the person with dementia take the medications on his or her own?
 - If not, who will help with medications?
 - Can the practitioner who prescribes the medicine adjust the schedule for taking it so family or home care team members are available to help?
 - Who will be responsible for overseeing changes in medications?
 - Is mail order or pharmacy delivery of medications preferable?
 - What kind of insurance coverage does the person have to help pay for medications?
- When medications are used, specific emotional symptoms should be identified and tracked so that the effects of the medication can be monitored. In general, it is best to start with a low dose of a single drug. The smallest dosage should be used for the least amount of time possible. Side effects require careful monitoring. Effective treatment of one core symptom may sometimes help to relieve other symptoms.
- The decision to use an antipsychotic drug needs to be considered with extreme caution — carefully weighing potential risks against potential benefits for the particular person and the particular situation. Sometimes medications can increase the frequency or severity of the symptom being treated. When considering use of medications,

it is important to understand that no drugs are specifically approved by the U.S. Food and Drug Administration (FDA) to treat behavioral and psychiatric dementia symptoms and FDA analysis shows that both conventional and atypical antipsychotic medications are associated with an increased risk of death in older adults with dementia. The FDA has asked manufacturers to include a “black box” warning on all antipsychotic medications. The warning describes the risk of death when people with dementia use these medications and includes a reminder that they are “not approved for the treatment of patients with dementia-related psychosis.” With any medication change, health care providers need to monitor patients carefully and be familiar with the risks and benefits of these therapies.

- Research evidence as well as FDA warnings and Centers for Medicare & Medicaid Services’ guidance on the use of antipsychotics show that people with dementia should only use these drugs when their behavioral symptoms are due to mania or psychosis, present a danger to the person or others, or cause the person to experience extreme distress, a significant decline in function, or substantial difficulty receiving needed care, which may be life threatening.
- Health professionals who specialize in non-pharmacological and pharmacological interventions for behavioral symptoms associated with dementia can help with diagnosis and treatment of severe or disturbing behavioral symptoms.

Decision-Making — Issues, Roles and Responsibilities

- People with dementia and family caregivers need information from knowledgeable professionals about: the signs and symptoms of dementia, the course of the disease, dementia as a fatal illness, causes of physical and behavioral symptoms, home environment design, safety, effective approaches to care, and community resources such as the Alzheimer’s Association. Using this information, the person and family can make the best decisions about care.
NOTE: A diagnosis of dementia does not necessarily mean the person does not have the ability to make decisions; the person should be involved as much as possible in his or her own care planning.
- The ability of a person with dementia to understand care choices and make decisions about care varies with the progression of the disease and the type of decision required.
EXAMPLE: A person may be able to choose that they want treatment but unable to choose among complicated cancer treatment regimens.
- People with dementia will have choices about who makes care decisions when they cannot, so it is important to find out who the primary decision-maker will be.
- Whenever possible, a family member should be designated as the primary contact for all members of the home care team. However, it is important to recognize that different family members can have different responsibilities.
- When more than one agency serves a person, coordination of care, interagency coordination agreements and communication are important.



ADVANCE PLANNING

- The goals of the person and family for end-of-life care provide the care team with direction for care planning. Ensure that an interpreter is available to assist with non-native English speakers for these important conversations.
- A surrogate needs to make decisions based on what the person would want, taking into consideration expressed preferences, values and past life patterns. When discussing goals, individuals and families need to consider and make decisions about the issues listed below:
 - The steps to take and who to contact when death is near or has occurred. The steps will vary based on the person's advance directives, if he or she has them.
 - Cardiopulmonary resuscitation (CPR)
 - Medical procedures and tests (e.g. surgery, blood tests, dialysis)
 - Increasing the level and complexity of care in the home
 - Hospitalization
 - Entry into a nursing home
 - Enrollment in hospice

- Use of hospital intensive care units and ventilators
- Artificial nutrition and hydration (feeding tubes and intravenous fluids)
- Use of antibiotics
- Use of preventive health screenings, medications and dietary restrictions

EXAMPLE: Colonoscopies and mammograms may not be useful for people who are at the end of life and cannot benefit from or understand these sometimes painful procedures.

EXAMPLE: Risks and benefits of medications may change when a person is near the end of life.

- Individuals and families need to discuss care for other diseases a person may have, such as diabetes and congestive heart failure, in relation to the severity of dementia.

EXAMPLE: Hospitalization to treat congestive heart failure during the end stages of dementia could be hard on the person and may not prolong life.

LEGAL AND OTHER IMPORTANT CONSIDERATIONS

- Decisions about treatments and tests need to be part of the care plan and translated into medical orders when appropriate. Some states and localities have protocols to implement translation into medical orders such as the *Physician's Orders for Life Sustaining Treatment (POLST)*.
- Individuals and family members should have an opportunity to rethink their decisions as the person's needs or condition change.
- Federal law requires providers who accept Medicare and Medicaid payment to document whether patients have advance directives and to provide them with information about their decision-making rights.
- Providers can help prepare for end-of-life care discussions by providing materials that can assist in making advance planning decisions.

- The appropriate provider (e.g. a social worker or nurse) needs to obtain signed copies of existing advance directives and make them available to the entire care team. A coordinated effort should be made to ensure that the documents go with the person if he or she enters a nursing home, assisted living residence or hospital.
- During care planning, discuss the person's choices about end-of-life care and any related doctors' orders such as "comfort care only," or "do not hospitalize." Based on these choices, the person and family need to know what the agency will do at the end of life.
- Families and home care providers need to understand that calling 9-1-1 or other emergency services will likely result in attempts to resuscitate a person when he or she has stopped breathing, unless a physician's "do not resuscitate" orders are immediately available. Family and providers need to agree about what they will do when the person is close to death.

HEALTH CARE PROXY DECISION-MAKER

- Advance planning cannot deal with all care decisions that must be made during the course of a person's dementia, so the role of a proxy decision-maker is important. All 50 states and the District of Columbia permit individuals to assign another person (or proxy) to make health care decisions on their behalf.

NOTE: By having a properly designated proxy decision-maker, complications that arise from disagreements among family members may be more easily resolved.

NOTE: Situations where the proxy seems to be acting against the person's best interest or a person with dementia has chosen the proxy under threat should be reported to the home care team for possible referral to adult protective services.

- Ideally, the proxy decision-maker is someone who knows the person's values and choices about end-of-life care. The person may also express particular values and choices in the document appointing the proxy.

- The proxy decision-maker will need complete information from and some education by the home care team when considering the trade-off between prolonging life and maximizing comfort after a medical crisis or major change in the person's condition.
- State law determines who serves as the proxy decision-maker if the person has not appointed one.

General Home Care Planning and Provision

CARE PLANS

- Effective care plans use information from the assessment to design a set of services that will meet a person's needs and maximize his or her independence. Services need to fit the needs and history of the person being served and be coordinated with the care that family and home care providers deliver.
- Care plans should build on the person's abilities and use strategies like breaking tasks into small steps, modifying the environment, and using adaptive equipment. Physical and occupational therapy services can help decrease the risk of falls, improve a person's mobility and his or her ability to carry out daily activities.
- Care plans need to ensure safety with walking, transferring and performing daily tasks.
- Effective care planning includes the person with dementia (whenever possible), family members and all staff, including direct care providers, who regularly interact with the person.
 - Ask family members to describe how they work successfully with the person in completing daily activities, and adopt these methods when providing care.

- When providers and family members understand the care plan and determine roles and responsibilities, they will be able to provide better care.
- The care plan stays useful over time if it is regularly updated and modified as a person's needs, abilities and wishes change.
- Care plans should identify family caregivers and address family caregiver needs.
 - Create a schedule with the caregiver that provides him or her with suggestions for self-care. Sometimes, caregivers do not set aside time to eat, rest, and address their own health and emotional well-being.
 - Provide dementia care training to family caregivers who need or want it. Offer referrals to physical therapists, speech language pathologists, and occupational therapists for strategies the family caregiver can use to help the person carry out daily activities. Consult with behavioral specialists when the person's behaviors are difficult for the family caregiver to manage.

PROVIDER APPROACHES

- People with dementia are most comfortable with a regular routine at home. Knowing a person's daily routines, such as how he or she likes coffee or tea and what time he or she gets up and goes to bed, is helpful information that will guide the care plan.
 - Going to bed at the same time every night, with the same routine, can make sleep more restful.
 - A schedule for use of the toilet that follows the person's usual toileting patterns can reduce accidents.
- When possible, consistent staff assignment (having the same direct care providers at the same time of day) creates a more predictable daily routine and can improve the quality of the relationships among direct care providers, people with dementia and their families.

2

Personal Care Guide



SOCIAL RELATIONSHIPS AND MEANINGFUL INTERACTION

Activities are meaningful when they reflect a person's interests and lifestyle, are enjoyable to the person, help the person feel useful, and provide a sense of belonging.

Dementia Considerations

- Like everyone, people with dementia need meaningful social relationships.
- Direct care providers need training and support to understand how to have good relationships with people who have dementia.
- Meaningful activities are important to dementia care. They can address underlying needs that can lead to behavioral symptoms, help people maintain their ability to carry out daily activities, help reduce behavioral symptoms, and improve quality of life.
- Every event or interaction between the individual and a provider is a potentially meaningful activity.

Care Goals

- Help the person with dementia have and sustain meaningful social relationships.
- Develop trust with the person by showing a sincere interest in the social relationships and activities he or she enjoys. A person with dementia can sense a care provider's lack of interest or impatience.
- Design meaningful activities that match a person's interests, choices and abilities and that providers or family do *with* — not *to* or *for* — the person so that he or she can have the best quality of life possible.

Recommended Practices

ASSESSMENT

- Determine whether the person initiates activities or needs prompting and invitation to take part. Many people enjoy various activities they would not necessarily begin on their own.
- A comprehensive assessment by the home care team gathers information from the family and helps home care providers understand which activities are meaningful for the person with dementia.

- To involve people in the most meaningful activities, determine their:
 - Ability to move (with and without assistance)
 - Daily routine and schedule
 - Capacity for mental stimulation
 - Ability to communicate (e.g. status of speech and hearing)
 - Interest in social relationships
 - Desire for spiritual participation
 - Cultural values
 - Work history and habits
 - Leisure interests and choices such as favorite music and movies
 - Opportunities for transportation to community activities
 - Need for referral to an occupational therapist, physical therapist or speech-language pathologist for an assessment and intervention plan
- Families and people with dementia should be invited to share with providers a life story that summarizes the person's past experiences, choices about activities and other aspects of daily life as well as his or her current abilities.
- Regular and ongoing assessments are needed because interests and abilities change. People with dementia can develop new interests and try new activities.

PROVIDER APPROACHES

- Social relationships and meaningful activities are the key to a good care plan.
- Providers consistently interact with the person with dementia as part of the care plan. The methods and strategies used can greatly improve the person's quality of life. Provide cueing and assistance to engage people directly.
 - Share something with a person; look at his or her family photographs, talk about a keepsake, or encourage the person to share part of his or her life story.
 - If appropriate, explain in understandable terms what is happening during a bath and offer reassurance such as, "I'm going to wash your arm now. You're doing great!" When working with a person who is functioning at a lower level, it may be better to use fewer words and more physical and non-verbal communication. For example, placing a hand on the person's arm and smiling.
- When preparing a meal, include the person with dementia in the process by helping him or her to participate in some way.
 - Based on the person's abilities, he or she could tear the lettuce, stir the soup or place the bread on the plate. It is important to have the person with dementia perform a task that he or she is capable of and can do safely.
 - The occupational therapist can do an assessment and determine the appropriate intervention.
- A person with dementia can relate to others, even if he or she has problems talking.

EXAMPLE: If a person's life story shows that he or she enjoys music, play music or sing a song that is familiar.
- Throughout the day, introduce activities that minimize behaviors such as confusion, agitation, and restlessness. Rest breaks should be integrated into the routine to reduce the potential for fatigue.
- Help make individuals with dementia more comfortable and secure in the environment by validating their thoughts, ideas and experiences.
- Promote independence in daily activities by structuring the environment and the task to match the person's level of functional and cognitive ability.

ENVIRONMENT

- The home environment can create opportunities for meaningful activity.
 - Encourage family members to develop a path that encourages walking outside in a safe environment.
 - Have family members set up a fish tank or display a colorful painting that could interest the person and facilitate conversation.
 - Assemble and offer items of interest like a basket of fabric swatches, greeting cards, calendars with attractive photos, or touchable items such as aprons, hats and safe tools.
 - Make comforting family photos available to the person.
 - Encourage family members to start a vegetable/ herb/flower garden that the person with dementia can help nurture.
- The environment should reduce a person's confusion and fear, and promote comfort and safety.
 - Ensure that activities occur in a quiet room.
 - Ensure good lighting and room temperature as well as comfortable seating for the person with dementia.
 - Attempt to decrease clutter and other distractions, such as background noise, in the environment.
 - Refer to an occupational therapist or physical therapist for a home safety assessment and recommendations for home modifications.
 - Monitor for safety issues such as wandering.



ACTIVITIES

- People need to use their skills during daily activities to remain as independent as possible.
 - Use methods like one-step verbal direction to help people carry out activities. For a person with dementia, participating in a cooking task is more meaningful than watching it. Depending on the person's ability, he or she might measure or mix the ingredients or hold the spoon.
- The outcome of an activity is not as important as the person's participation in it.
 - Gardening can be pleasant whether or not a plant grows.
 - Dusting can be satisfying even if it is ineffective.
 - Washing the car, even if it is not dirty, can be fun.
- Offering activities that take into account a person's abilities can promote involvement. An occupational therapist's or speech-language pathologist's assessment provides specific information regarding the person's cognitive abilities which can be used to match abilities to activities.
 - Word games may be successful for some people with dementia but upsetting for others.

- Opportunities for involvement in the community are important to feeling part of it.
 - When appropriate, support activities such as attending a play, doing a community service project, or playing with local children through a special program.
 - If a faith community is important, be sure to help the person remain connected with his or her place of worship. Help the faith community understand dementia by asking the local Alzheimer’s Association chapter to provide education to the clergy and congregation.
- The activity’s length needs to fit the individual’s abilities.
 - Thirty minutes or less of one activity is best for most people with dementia.
- Adapt activities to the person’s skills and abilities. Some people cannot sit through an entire activity but may enjoy just a part of it.

EXAMPLE: A person may not be able to participate in the entire preparation of a meal, but can help serve the meal or set the table.

- People who cannot move easily can enjoy activities like listening to music, watching a movie, reminiscing, sensory stimulation and seated exercises.



PAIN MANAGEMENT

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.

Dementia Considerations

- 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 non-verbally. As verbal ability declines, people with dementia rely more on non-verbal communication. This can include behavioral symptoms and resistance to care. These symptoms can lead to the inappropriate use of psychotropic medications.

Care Goals

- Improve pain assessment and treatment by routinely assessing pain as the “fifth vital sign” — just as a nurse, home health aide, or certified nursing assistant would measure blood pressure, pulse, respiration and temperature.
- Enhance a person’s quality of life by controlling or minimizing pain and improving his or her function and ability to socialize.
- Tailor pain relief methods to each person’s needs and risks, and adjust treatment as the person’s condition changes.

Recommended Practices

ASSESSMENT

- Pain assessment should occur regularly, especially when people have health problems, such as arthritis and cancer, that are likely to result in pain or they exhibit pain in any way (e.g. facial grimace, moaning, or guarded extremity).
- There are many tools that measure pain for people with dementia. Identify the one that works and use it consistently as long as it works for the person.
- Effective pain assessment gathers information about:
 - Where the pain occurs and whether it moves to other locations
 - Type of pain and what makes it better or worse
 - Effects of pain on the person
 - Causes of pain
 - Whether pain is quick onset or persists over time
 - Severity of the pain and whether it interferes with daily functioning
 - Positive and negative effects of treatment
- For people with dementia who cannot answer questions about discomfort or pain, all home care providers must watch for signs 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, 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.
- All providers need to help identify a person’s pain and communicate the signs to their supervisor or to the home care team.
 - When people are in pain, they need to see a qualified health professional who can manage the pain effectively.
 - Improvements in pain management can not only decrease discomfort but also improve functional abilities, mood, appetite, sleep, and overall quality of life.
 - Pain assessment and management should try to incorporate an interdisciplinary approach. Qualified health professionals, such as physicians, nurses, psychologists, social workers, and physical and occupational therapists, can work together to formulate appropriate non-pharmacological approaches including the use of positioning, heat, cold, aromatherapy, music and distraction.
 - The doctor or pharmacist should be asked about the side effects of any drugs used to treat pain as well as ways to prevent or manage them.

PROVIDER APPROACHES

- Prevention of pain is the first defense against it.
 - Promote patient comfort and prevent painful conditions, such as bone fractures, pressure ulcers and skin tears, by being careful when providing care.
 - Avoid having the person with dementia stay in one position too long or move too quickly.
- Pain *may* be prevented through the regular or scheduled use of medications to relieve pain.
- Persons with cognitive impairment may not volunteer information about their pain as often as persons without cognitive impairment, but this does not mean they do not experience pain as often. One approach to circumvent this issue is to use routine or scheduled pain medications. For continuous pain, medications are best given on a time-contingent, around-the-clock basis. When persistent pain occurs, approaches that do not involve medications can be helpful.
 - Useful ways to ease pain include: relaxation, physical activity, 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).
- Pain medications may be necessary if these therapies do not work.

NOTE: Doctors, in conjunction with pharmacists and other licensed practitioners, will decide how and when to use medications to relieve pain based on the severity of the pain and the person's past experience with medications. Side effects of some medications may cause an increase in forgetfulness or sleepiness. Most often, a pain medication without these side effects can be identified.

- Some pain medications can cause constipation, so a provider will want to include stool softeners when opioids are given.
- At the end of life, providers may become concerned that opioids will hasten death. This is not the case. Opioids can actually help ease a person's pain during the dying process. Consultation with an expert in hospice and palliative medicine can help ensure that a person is as comfortable as possible.
- When considering pain medications in the home setting, it is important to take note of any over-the-counter pain medications the person may be taking. Consult with a physician to determine appropriateness and potential interactions.
- Pain medications are often controlled substances that require additional attention. Controlled substances may require a hard-copy prescription for every "refill" depending on the type of medication. Providers should be proactive about requesting "refill" prescriptions so that a patient does not run out of pain medications before the refill is available. In addition, controlled substances should be securely stored in the home. Doctors, pharmacists and nurses are available to help with questions and concerns regarding the proper disposal of unused pain medications.



PERSONAL CARE

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.
- 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.

Recommended Practices

ASSESSMENT

- Use assessment to determine the person's habits, choices and daily schedule in order to ensure the best possible outcome with personal care.
- Learn from family members the person's needs and choices about care.
- Observe the person while they do a task to find out where they need verbal or physical help.
- Evaluate the benefit of written cues (e.g. single-word reminders) to help the person understand tasks or schedules.
- Assess the person's abilities and capacity for independence, with a focus on promoting safety.
- Conduct a functional assessment to determine not only the person's abilities, but also those of the family caregiver, including their willingness and capacity to take part in care. You can even use a caregiver "self-assessment" so they acknowledge their own role and ability.

PROVIDER APPROACHES

- 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.
 - Encourage, reassure and praise the person.
 - Watch for unspoken communication.
- EXAMPLE:** A person in pain 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 a person wants to put on his shirt after his shoes and socks, go along and provide assistance.

Bathing

- Bathing can be a frightening experience for a person with dementia 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.

PROVIDER APPROACHES

- Find out how family caregivers successfully bathe the person with dementia and what the person's choices are related to bathing. For example, he or she may be accustomed to a tub bath and be afraid of showers.
- 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 a 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.
- Consider the frequency of bathing. It may not be necessary for individuals to bathe every day.
- Be gentle. A person's skin may be very sensitive. Avoid scrubbing, and pat dry instead of rubbing. A hand-held shower may help to wash hard to reach areas.
- Wash the most sensitive areas last, including the head, face and perineal area.
- 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. Be flexible; the person may also enjoy going to the barber or beauty shop.

ENVIRONMENT

- Recommend installing grab bars on the wall and tub edge. Place non-slip mats on floors. Use a tub bench or bath chair that can adjust to different heights. Consult with an occupational or physical therapist for proper placement of grab bars and adaptive equipment (durable medical equipment).
- Use only two or three inches of water in the tub, and test the temperature in advance.
- Prepare the bathroom in advance by gathering supplies like towels, washcloths, shampoo and soap. Check the room temperature to make sure it is not too cold.

Oral Care

- 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 and pneumonia.

PROVIDER APPROACHES

- 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.
- Monitor daily oral care including brushing teeth or cleaning dentures after every meal. Gently brush the person's gums, tongue and roof of mouth.
- Recognize the importance of dentures; understand that some people prefer not to use them when eating.
- 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.

EXAMPLE: If a person cannot swallow regular liquids, they should not be given a cup of water to rinse after brushing as this may cause aspiration of the liquid.

- Keep up with regular dental visits for as long as possible.
- 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 a 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.

ENVIRONMENT

- Provide dental care in a familiar environment or one that will provide environmental cues about the activity.
- Consider calm music, comfortable seating, and other approaches to put the person with dementia at ease.

Dressing

PROVIDER APPROACHES

- 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.
- 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 snaps or zippers 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.
- Make sure the person has comfortable, sturdy non-slip shoes.
- Ensure that the person has enough time to dress before leaving the house. Avoid having to rush.

- If a 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.
- Clothing can be used as a conversation starter.

EXAMPLE: A direct care provider can compliment the floral pattern in a woman's dress or ask the woman what she thinks of the pattern. This kind of conversation can help keep the person involved in dressing.

ENVIRONMENT

- Keep closets free of excess clothing. One strategy is to be sure only seasonally appropriate clothes are available.
- Limit clothing choices to reduce confusion and the burden of decision-making.
- If appropriate, provide assistive devices to promote independence in dressing. Be aware that, under some circumstances, using assistive devices can be too overwhelming and complicated for the person with dementia.
- Response to mirrors can be varied. Some people becoming agitated or confused by the "person in the mirror." Steps should be taken to minimize this confusion, covering mirrors if necessary.

Grooming

PROVIDER APPROACHES

- Support grooming routines by helping the person to maintain his or her routine (e.g. continue using a man's favorite shaving cream or a woman's favorite makeup).
- Know the person well enough to know their grooming choices. For example, what hairstyle does the person prefer?
- Perform tasks, such as hair combing, alongside the person and encourage the person to copy your motions.

- Promote safety by carefully determining when shaving becomes a risk for the person with dementia and should be done by someone else.

ENVIRONMENT

- Use safe, simple grooming tools such as cardboard nail files or electric shavers.
- Provide a chair or comfortable area for grooming.
- Remove excess clutter from the counter or cabinet.

Toileting

- 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 bowel; this called incontinence. Causes include 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.

PROVIDER APPROACHES

- Assess for signs of urinary leakage or incontinence including: the smell of urine in the home, soiled clothing, use of peripads or paper towels in undergarments, or increased privacy around laundering of undergarments.
 - Assess bowel pattern by determining how frequently a person typically goes to the bathroom. Help him or her maintain that pattern, while monitoring for safety.
- **EXAMPLE:** A person may move his or her bowels every one or two days.
- 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.

- Identify when accidents occur and plan for them by getting the person to the bathroom before that time.
- Exercise, a diet high in fiber, and sufficient fluid intake are important to preventing constipation. Stool consistency is the key indicator for when a person is not getting enough to drink. Light straw-colored urine generally means the person is well-hydrated; yellow or amber-colored urine could mean dehydration.
- If exercise, diet and fluid intake do not maintain bowel regularity, work with a physician or nurse to develop a regimen for laxative use that is gentle and predictable.
- Be supportive by helping the person retain a sense of dignity. Reassure the person to reduce feelings of embarrassment.

ENVIRONMENT

- Remove obstacles by ensuring clothing is easy to remove.
- Install a nightlight in the room to guide the way to the bathroom.
- Keep a light on in the bathroom to improve visibility.
- Ensure that slippers have adequate stability and traction.
- Move furniture or other obstacles that may block the path to the bathroom. Keep in mind that if a person uses furniture or objects to assist with balance, moving those items can increase fall risk.
- Create visible reminders. Post a sign or picture of a toilet or make the toilet more visible.
- Consider incontinence products (e.g. adult briefs or incontinence pads).
- 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 the disease. A person with dementia may not be able to initiate the task of eating, but if a spoon is placed in his or her 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.
 - 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 higher risk for aspiration (inhaling food and/or liquids into the lungs).
- Ensuring that a person eats and drinks enough will promote good health and help prevent behavioral symptoms and physical decline.
- A person with dementia may refuse to eat or drink because of physical or emotional conditions at the end of life.
- People at different stages of dementia may have different reactions to food or liquids. It is important to gauge a person's response and develop eating rituals and approaches accordingly.
- A person with dementia may have difficulty recognizing food or liquid, even when it is in his or her mouth.
- Eating is a cultural experience. It helps build personal connections through the shared experience of serving and receiving food or liquid.
- Family caregivers are often heavily involved in food choice, 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 the person eat and drink what he or she likes, and provide food that meets dietary needs to promote health and safety.
- Monitor the person for changes in eating and drinking habits and help him or her avoid significant weight loss or gain (five percent or more in one month or ten percent or more in six months). Any significant changes should be communicated to the physician.
- Help to make mealtimes pleasant and enjoyable; involve family when the person and family are amenable.

Recommended Practices

ASSESSMENT

- In addition to gauging a person's ability to eat or drink, assessments should determine: the person's eating or drinking habits and preferred foods, how family caregivers help the person eat or drink, quality of food preparation areas, availability and accessibility of groceries, safe food storage and the ability to manage nutritional needs and choices as key components of good nutrition care.
- Assessments should also note warning signs such as:
 - Difficulty chewing and swallowing, or changes in swallowing ability. Signs of difficulty include drooling, coughing, choking, and pocketing food in cheeks or continuous chewing.
 - Poor dental health, such as tooth pain and bleeding gums.
 - Poor use of knives, forks, spoons, dishes and cups.
 - Lack of attention to a meal or wandering away during it.
 - More than a quarter of the total food portion left over after a meal.

- Poor balance and coordination during a meal.
- Unexplained weight loss or gain.
- Dehydration or reduced fluid intake.
- Note any needed dietary restrictions, as there may be interactions with medication.
- If the assessment finds problems, the care plan needs to help address them.
 - Refer the person to a registered dietitian who can define and prioritize methods of dealing with nutritional problems.
 - People who have swallowing difficulties may need assessment by a qualified speech-language pathologist.
 - To the extent possible, help the person obtain professional dental care on a regular basis to deal with dental pain or other problems that might interfere with eating.
- Adaptive eating utensils, plates and cups, or finger foods may help people eat or drink. Refer to an occupational therapist for recommendations.
- Adjusting the size, shape and texture of food may help a person eat.
- Some people with dementia 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.
- Ensure that seating deals with balance problems. Proper positioning can be a key to a successful meal.
- It is ideal for direct care providers to sit, make eye contact, and speak with people when helping them with meals.

PROVIDER APPROACHES

- 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.
- Various activities can help ensure that people have a good appetite and enjoy a pleasant meal.
- EXAMPLE:** Involve the person in making the meal or setting the table, or create a "happy hour" to encourage drinking of fluids.
- 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.
 - If assessment shows that the person can eat or drink on their own at a slow pace, provide verbal or physical cues to eat and drink and enough time to finish eating or drinking.
- A person with dementia may not remember that he or she has eaten and could tend to overeat. If this happens, it is important to limit access to food between meals, stick to a meal schedule, provide small helpings, and monitor food intake.
- NOTE:** These steps may increase behavioral symptoms which can be handled with more activity.
- Consider any over-the-counter supplements, like vitamins and herbs, a person is taking and consult with a physician for guidance on appropriateness.
- Offer nutrient-dense foods whenever possible to maximize the quality of the intake.
- People in the end stages of dementia may lose weight either 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.

NOTE: People should not be forced to eat or drink more than they want. Artificial food and fluids, as through a feeding tube, are not necessary when the person or family choose not to use them. When making decisions about enteral nutrition via a feeding tube, people should balance the benefit of intake with potential risks. Tube feeding may be very helpful when a person has an inability to swallow due to conditions such as stroke or esophageal cancer. However, when persons are in the end stages of dementia and lose the ability to swallow or have lost interest in eating or drinking, the risks of enteral nutrition via a feeding tube likely outweigh potential benefits. Research shows that these risks include aspiration (inhaling food or liquid into the lungs), infections, and diarrhea. The person may also try to remove feeding tubes because they are uncomfortable.

ENVIRONMENT

- People should have a pleasant, simple place for meals.
 - Avoid mealtime interruptions and reduce noise, the number of items on the table, and the use of complex tablecloth patterns.
 - Remove unnecessary papers and objects on the table. A person's attention to food can increase by ensuring visual contrast between plate, food, and table.

EXAMPLE: Use a light-colored plate on a dark placemat.

- Individuals need opportunities to drink fluids throughout the day.
 - Make sure fluids, such as popsicles, sherbet, fruit slushes and water, are always available.
- Make snacks available, accessible and visible at all times to promote increased eating or drinking.
- Food storage and safety are important considerations in the home environment. Be sure all perishable food is kept in the refrigerator at all times and spoiled food is disposed of regularly.

- Store cleaning supplies separately from food so that cleaning agents will not be mistaken for food items.
- Remove items from the environment that may be mistaken for food.

EXAMPLE: A bowl of potpourri on a table in the living room.

- As a person's ability to eat or drink declines, food or beverages should be made manageable to help a person eat or drink.
- Assistance may be needed when a person cannot use utensils. Try adapting foods to promote independence.

EXAMPLE: If a person cannot handle knives, forks or spoons, try foods that can be picked up with the fingers. Consult or refer to an occupational therapist for recommendations.

FALLS

Falling is accidentally coming into contact with the ground or another surface, like a table. Falls may occur with or without injury and often result from a loss of balance.

Dementia Considerations

- People with dementia have a greater risk of falling because they can have problems seeing, thinking, moving, and balancing.
- The cause of falls can be related to the person's abilities or home environment.
- Personal risks include: history of falls, depression, vision problems, muscle weakness, fear of falling, multiple medications, being tired, blood pressure problems, incontinence, and being unable to move or having difficulty with movement.
- Environmental risks can include:
 - Confusing environment and clutter
 - Slippery footwear

- Unsafe equipment
- Lack of stable furniture or handrails
- Surfaces (e.g. floor, stairs, or ground) that are uneven, slippery or have glare
- Poor lighting, especially at night
- Weather conditions that may result in slippery surfaces, or heat exhaustion
- Rugs and doormats
- 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. This is important to think about when considering new medications or changes in dosage.

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.

- Falls may cause many negative effects, including broken bones and bruises, concussions, hospitalization or nursing home placement, and fear of falling that can limit a person's willingness and ability to move or walk.

Care Goals

- Encourage safety and maintain a person's ability to move within a living space by decreasing the risk of falls and related injuries.
- 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.

Recommended Practices

ASSESSMENT

- Regular assessment is important to determine whether a person is likely to fall and what might cause a fall. Good assessments include:
 - Consultation with a physical therapist if the person requires assistance with walking, balance or muscle strengthening. Consultation with an occupational therapist if the person requires assistance with daily activities or energy conservation. The consultations may result in recommendations for equipment or devices to assist the person or family member.
 - History and patterns of near-falls, recent falls, and fall-related injury
 - Mental impairment and ability to safely use aids, such as walkers
 - Ability to move safely within a space
 - Ability of the body to sense position and movement
 - Vision and perceptual changes
 - **NOTE:** Vision problems may be related to eyeglasses that no longer work for the person with dementia.
 - Ability to perceive touch
 - Medical problems that may contribute to falls (e.g. problems with balance, pain, infections, heart disease, osteoporosis, and need to urinate often at night)
 - Hallucinations and delusions
 - Presence of physical restraints or objects in the environment that reduce a person's ability to move about
 - Nutritional health and recent weight loss
 - Current drug use, medication side effects or recent change in medications
 - History of or current alcohol or drug abuse or withdrawal symptoms
 - Emotional conditions such as depression and anxiety

- A person's life and work history, or daily habits that could lead a person to try something that may result in falls
 - EXAMPLE:** A person who was in the furniture business might try to move heavy furniture and increase the risk of falling.
 - EXAMPLE:** A person may climb on a stool to reach something on a high shelf. Move these items to a lower level.
 - Environmental assessment includes:
 - Environmental layout (arrangement of furniture/ objects in space and ease of getting around)
 - Lighting and glare
 - Door thresholds
 - Barriers to safe movement at home
 - Usability and safety of kitchen, bathroom and dining room
 - Sturdiness and visibility of handrails and furniture
 - Contrast between toilet and sink, and wall and floor
 - Safety and working condition of equipment and fixtures (e.g. bedside toilets, shower chairs, wheelchair brakes)
 - Use of aids including canes, walkers and wheelchairs
 - Bathrooms with non-slip surfaces
 - Big windows or glass doors that people can run into
 - Floor surfaces, textures and patterns
 - EXAMPLE:** A blue-and-black border may look like a river or a hole.
 - Rugs that could cause the person to trip (e.g. throw rugs and rugs with worn or frayed edges)
 - Recent changes in the home, due to safety concerns, that may make the environment seem unfamiliar
 - Clothing or attire that puts the person at risk such as shoes with heels, slip-on shoes and loose fitting clothing. Examine shoes and slippers regularly for smooth or worn soles that may be slippery.
 - Use a system to identify falls, fall patterns, and patterns of risky movement. Follow up with a family care plan meeting to provide education about falls and to decide how to deal with risk of falls.
 - When needed refer the person to a qualified professional who can assess the person's mobility and ability to use safety and fall prevention methods.
 - Refer to occupational therapy or physical therapy for a comprehensive home evaluation with recommendations for home modification.
- PROVIDER APPROACHES**
- Based on the assessment, develop a care plan that encourages mobility and safety while preventing or reducing injuries. Update the plan if the person begins to fall more frequently or there is a change in patterns. Involve family or other caregivers in planning so they understand the person's condition as it changes.
 - Training direct care providers about dementia care is an important step toward helping to reduce falls. Effective direct care provider training includes:
 - Risk assessment
 - Identifying and observing personal needs and behaviors, such as wandering, that may increase the risk of falls or fall-related injuries
 - Understanding that movement and physical activity is important and should be encouraged
 - Understanding the risks and benefits of various fall prevention methods
 - Understanding the benefits of physical activity for improving a person's physical health
 - Proper use of safety aids, like walkers
 - Safe ways to lift and transfer people

- Many ways to help prevent falls exist.
 - NOTE: Methods that are multifaceted and based on individualized assessments have the best chance of reducing falls.**
 - Exercise that promotes sit-to-stand activities, balance, and walking as part of the daily routine can help preserve a person's mobility.
 - To reduce falls related to urgent trips to the bathroom, consider using an individual toileting schedule or bedside toilet. Consider clothing that is easy for individuals to take off when they have to go to the bathroom.
 - Reduce fall risk by ensuring that the person has eyeglasses on and hearing aid in if required. Bring in natural light and nightlights and minimize tubing if a person has medical treatments like oxygen tubing and catheters.
- Assigning the same provider to a person with dementia increases the provider's familiarity with the person and his or her risk for falls.
- Assess for dehydration by monitoring for sudden weight loss or increasingly dark urine.
- Encourage proper use of aids, such as a walker.
 - NOTE: Some individuals may need home care providers to walk with them at all times in order to prevent falls.**
- Encourage use of assistive devices to promote safe walking. For example, fill the basket of a walker with personal items so it is familiar to the person.
- Encourage use of a sturdy chair with arms and a seat that is high enough to ease standing up and sitting down. Do not use chairs on wheels.
- Promote a regular sleep/wake cycle by keeping bedding dry, ensuring enough daylight, and matching the sleep/wake cycle to a person's habits.
 - Ensure a comfortable sleep environment with a good quality mattress, comfortable temperature and low noise level.
 - Help a person choose between incontinence products (to promote uninterrupted sleep) and an individual toileting schedule.
- Promote communication among all family and home care team members (including physicians) about any changes to medications that may include side effects that are fall risks. Encourage all family members to keep an updated list of medications and review it with physician and pharmacist at every appointment. Encourage them to ask why new medications are prescribed and what side effects can be expected.
- Educate family members on the safe use of ambulatory and assistive devices.
- Have a regular exercise or walking program, for those people who can safely take part, to maintain or improve function, posture and balance.
 - Develop walking programs around a person's need to get someplace, such as walking to and from the dining room, instead of using a wheelchair.
 - Regularly walk outside in the sunlight (also an opportunity for socialization).



Environment

- Adjust bed, wheelchair, other chairs and toilet heights to help prevent falls. Existing safety guidelines recommend that toilet height be at about knee level.
- Understand that a person with loss of balance will grab onto anything within reach. Ensure that stable handholds are available by providing such items as grab bars and railings.
- Make sure furniture is sturdy and in good condition.
- Whenever possible, ensure that floors are slip-proof, especially in bathrooms and next to the bed.
- Encourage use of footwear that is non-skid and provides a wide base of support.
- Ensure good lighting.
 - Increase the person's ability to turn on lights by installing motion-activated lighting or sensor lights.
 - Install nightlights between a person's bed and bathroom.
- Individuals with early dementia may be able to use personal emergency response systems to alert family caregivers or providers to emergencies.
- Encourage ongoing monitoring of the person, using frequent contact, silent alarms or an alert system to notify home care providers or family caregivers when a person at risk of falling attempts to leave a bed or chair.

CAUTION: Alarm systems can restrict a person's movement. Some people may be afraid to move for fear of setting off an alarm; others may become agitated when the alarm sounds.



WANDERING

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.

Dementia Considerations

- Wandering is not necessarily a behavior that must be stopped. Movement can be beneficial.
- Wandering can help a person stay in touch with others, find interesting things to do, or keep mobile. Wandering can help a person remain physically fit and in a better mood. It can help a person sleep better at night.
- Wandering can be dangerous when a person leaves home alone or goes into unsafe areas. Physical problems, such as injuries, health risks (e.g. hypothermia, dehydration), agitation, or death, can occur.

- 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, infection or medication effects
- 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
- Sometimes a person may try to leave home. The event may stem 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. The person may be drawn outside by a sunny day, or a desire for fresh air or a daily walk.

NOTE: Some people may not actually be trying to leave; they may simply see a door and decide to go through it.

NOTE: Physical restraints do not increase safety for people who wander. In fact, restraint use may increase the chance of injury.

Care Goals

- Help a person move about safely and independently and understand the difference between safe and unsafe wandering.
- Assess the causes of wandering and address any unmet needs that may be inducing the behavior.
- Know effective interventions to prevent unsafe wandering or successful exit seeking.
- Be prepared to respond if an unsafe wandering event occurs.

Recommended Practices

ASSESSMENT

- 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.
- Determine each person's need and ability to move about, and identify the possible risks (e.g. becoming lost) by assessing:
 - Whether wandering is new
 - Wandering patterns, such as time of day it happens, events or places that cause it
 - Medical conditions that may cause wandering, such as urinary tract infections, pain, or constipation
 - Side effects of certain medications (e.g. an antipsychotic that may make a person restless)
 - Other needs such as hunger, the need to go to the bathroom, or boredom
 - Mental abilities, especially safety awareness and being impulsive
 - Vision and hearing
 - Ability to move
 - Person's daily routines and patterns, including sleep and toileting patterns
 - Person's life history, including past jobs and hobbies
 - Emotional conditions that may relate to wandering, such as anxiety or depression
 - Environmental hazards such as poor lighting, throw rugs and uneven floors
 - History of recent falls or near falls
 - The person's footwear and clothing
 - The person's access and response to safeguards, such as video monitors, sensors, door alarms, access to handrails and places to rest

- Assess the home to determine if it meets the needs of the person who wanders. A good environment has:
 - Opportunities for safe wandering and interesting activities
 - A daily routine that includes regular physical exercise and access to fresh air whenever possible
 - Locked doors with hidden keys
 - A plan for what to do if the person leaves home alone or if the person's whereabouts are unknown

PROVIDER APPROACHES

- If the person has memory loss and is mobile (either on foot or by other means), enroll 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.
- Discuss with family available technological solutions such as Alzheimer's Association Comfort Zone® powered by Omnilink, designed to give caregivers real time access to view a person's location on a map, the ability to set up zones and receive alerts (text or voice) when the person has left a zone, monitoring assistance and access to medical health records in the event of an emergency.
- Based on the assessment, develop a care plan that encourages movement and safety. Update the plan as the person's wandering patterns change. Involve family or other caregivers in planning so they understand the person's condition.
- Assign the same direct care provider(s) to work with a person who has dementia so that they can get to know each other and develop trust. When temporary or permanent changes in direct care providers are necessary, arrange for the current

direct care provider to introduce the new direct care provider to the person with dementia.

- Ensure that all providers know if a person tends to wander, the risks related to wandering, and why it occurs.
- Ensure that people are able to move about freely and remain safe.
- Ensure that people who wander have enough food and fluid. This may include offering food and drinks while they are "on the go."

NOTE: This is particularly important for people who cannot stay at the table during meals.

- Providers have many ways of reducing unsafe wandering, including:
 - Identifying a person's needs and wishes, and helping him or her do related, suitable activities.
 - Using a preventive approach to unsafe wandering.
 - For those who wander when needing to use the toilet, schedule visits to the bathroom based on the person's patterns and use cues to help the person find the bathroom quickly.
 - Involve the person in activities that promote friendships and have meaning, based on the person's abilities, choices, interests and history or hobbies.
 - Be prepared for times of day that trigger wandering, such as dusk.
 - Take people outside regularly (daily if possible), except during unsafe weather, such as very hot or cold temperatures or when the ground is slippery after snow or rainfall.
- Go with wandering individuals when they may be unsafe or substitute another activity.

EXAMPLE: A woman heads for the door at 3:00 p.m. and says that she must get home to meet her daughter after school.

DO: Begin by offering to help. Ask the woman about her daughter, or what kind of snack she would like to prepare and offer to help her prepare it. Engage her in an activity every day at 2:45 p.m. to redirect her attention before the behavior occurs. The goal is for the person to perceive the provider as an understanding and supportive person.

DON'T: Begin by telling her that she cannot go out or that her daughter is now grown up. Do not explain or try to be rational with her. The goal is to avoid unnecessary confrontation and have the woman perceive the provider as supportive.

- If an alarm system is needed to alert the family or provider when a person is trying to leave home, choose a system that is least disruptive or upsetting to the person.

NOTE: Chair, bed, and personal alarms that a person can hear may stop all movement, not just unsafe attempts to stand or walk without help. The person may try to get away from the alarm causing them to wander. The alarm may cause agitation or other behavioral symptoms.
- Train all providers on the problems of unsafe wandering, ways to keep person engaged and at home, and what to do when a person is lost.
- Keep a list of the places a person may wander to — past job locations, former homes, a place of worship, or a restaurant.
- Work with the family to put a search plan in place and activate it as soon as a person's location is unknown. An appropriate search and response plan includes:
 - Recent photos of the person with dementia and a list of former addresses to be provided to law enforcement personnel when a person is lost.
 - Notification of family and law enforcement personnel as soon as a person is missing and a process to ensure that personnel receive the missing person's photo and home address along with a description of clothing worn and other relevant information.

- Notification of Medic Alert® + Safe Return® to mobilize an immediate response.
- An organized search of the home and its surroundings. Understand that a person with dementia may not respond when his or her name is called.

ENVIRONMENT

- When possible, encourage family members to create indoor and outdoor paths that are free of barriers and have interesting, safe places to explore and comfortable places to rest. Paths need to be well lit without shadows or pools of bright light. Have window coverings that prevent glare but allow light. Ensure that transitions from pathways onto grass and other areas are smooth with no uneven surfaces.

EXAMPLE: A hallway in a home could have a rummage basket at one end for the person to explore.
- Create areas with recreational opportunities, like photograph albums that people can explore with home care providers or family.
- Provide activities, such as dance, exercise or rocking, which can replace wandering.
 - Use a safe gliding chair that has a wide base and does not tip easily.
- Provide cues to help people who wander know where they are. Cues can include large visual signs or pictures for bathrooms.
- 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.

3

Safety and Personal Autonomy



It is obligatory to protect a person with dementia from seriously harmful consequences, and it is equally obligatory to respect his or her competent decisions. Neither law nor ethics allow interference with a competent person's choices.

In general, respect for the autonomy, freedom and choice of the person with Alzheimer's disease or a related dementia, to the extent possible, is ethically important and the appropriate alternative to unnecessary coercion. People with dementia should be allowed to exercise their remaining capacities for choice, consistent with their cultural expectations. Denying this free exercise challenges their independence and dignity.

Dementia Considerations

- Restraints are sometimes used because of the mistaken belief that they are necessary to ensure safety, provide physical support or prevent falls.
- Physical restraints include any method or device that limits a person's freedom to move or access his or her body and/or cannot be easily removed. It is the *effect* of the method or device on the person that causes it to be a restraint.

NOTE: Casts, braces and bandages that are used during medical care may not be restraints.

- Examples of physical restraints include:

- Side rails on beds

NOTE: Sometimes people use "quarter rails" or "half rails" to move in bed.

- Limb and waist restraints
 - Hand mitts
 - Geri-chairs
 - Over-the-bed tables and trays that cannot be removed without help
 - Chairs or recliners that do not let a person get up on his or her own
 - Keeping a person in a closed or locked area for long periods of time
 - Positioning a wheelchair so that the person cannot move it or get out of it
- Physical restraints generally harm people because they have bad effects on a person's body, ability to walk, get food and fluids, change position, use the toilet and socialize.

NOTE: Persons who experience confusion can get caught between the bed rails and the mattress and suffocate.

- Using restraints may cause death, injuries, falls, physical weakening, incontinence, poor nutrition, dehydration, skin tears and pressure ulcers, heart problems, and infection.
- Restraints also cause distress and behavioral symptoms. People with and without dementia experience emotions ranging from frustration and anxiety to anger and terror when they are restrained or view restraints as obstacles.

Care Goals

- Consider alternatives to avoid use of restraints in the home.

NOTE: Temporary restraints may be needed if a medical professional determines they are necessary for the safe handling of a medical emergency. For example, a person experiencing delirium may need restraints for medical assessment and treatment.
- Identify problems that have led to restraint use in the past, and address them using other methods.
- Educate direct care providers and family members about methods they can use to prevent, reduce and eliminate restraints.
- Understand the needs of family and other care team members, and schedule and provide access to respite care services when they need to leave the home (e.g. to run errands).

Recommended Practices

ASSESSMENT

- Use assessment to find out each person's life history, habits and choices to help promote independence.
- Monitor for any changes or a need to intervene.

EXAMPLE: An over-the-bed table may be helpful and appropriate for eating. However, if that table remains in place for a length of time, it may be considered a restraint.

PROVIDER APPROACHES

- The key to avoiding restraints is for home care providers to know the person; regular assignment of providers to specific people encourages this practice.
- Effective care planning involves knowing a person's abilities and understanding how to use them to avoid wandering and falls that can lead to unnecessary restraints.
- Effective home care provider education about restraints includes:
 - Definition of restraints
 - Benefits of restraint-free care
 - Myths about restraints, including the idea that restraints are an effective way to ensure safety
 - Negative effects of physical restraints on individuals and home care providers
 - Assessment and care for people with behavioral symptoms, such as agitation
 - Individual rights and the legal aspects of restraint use
 - Agency restraint policy and procedure for use in emergencies

- Effective family education about restraints includes:
 - Definition of restraints
 - The negative effects of restraints
 - Myths about restraints including the idea that restraints keep people safe
 - Legal aspects of restraint use
 - Support of personal choice and freedom to move
- Home care providers can use creative solutions to meet a person's needs related to safety, behavioral symptoms, and physical support.
 - When people slide out of their wheelchairs because they are trying to move, place them in lower height wheelchairs without footrests or with footrests in the closed position so their feet touch the floor.
 - Use day and night-time activities to improve a person's well-being and decrease behavioral symptoms.
 - Seek consultation from appropriate professionals to eliminate the need for restraints by treating any physical, mental or sensory impairment.
 - Disguise and protect wounds so the person will not disturb bandages or healing.
- When using restraints during a medical emergency, home care providers need to get orders from the person's doctor and notify the family member or health care decision-maker as soon as possible. Home care providers should begin medical evaluation and treatment as ordered, call emergency services, or get the person to a health care facility.
- If a person is being restrained in his or her home, supervisors need to establish an interdisciplinary team to determine whether to report the restraints as elder abuse to the state's Adult Protective Services Agency, carry out a plan for getting rid of restraints, or recommend other care or living arrangements for the person with dementia.

ENVIRONMENT

- The environment can be modified so that it is restraint-free.
 - Use chairs that have the right height, depth, and support so a person can be comfortable and safe.

EXAMPLE: A person may prefer a recliner but require assistance to get out of it. Be sure to be available at these times. Consider using something like a toileting schedule for these occasions or use the opportunity to take a walk or exercise break.
 - Use a wheelchair only when needed for transportation.
 - Consult an occupational therapist to get advice about adjusting the person's environment and equipment to better meet his or her needs.

4

Home Safety



Dementia Considerations

- Alzheimer's causes a number of changes in the brain and body which may affect safety. Depending on the stage of the disease, these can include:
 - **Judgment.** A person may forget how to use household appliances or dress inappropriately for the weather (e.g. wearing several layers on a warm day).
 - **Communication.** A person may not understand a written warning or, in later stages of the disease, a verbal warning.
 - **Sense of time and place.** A person may get lost on his or her own street and be unable to recognize or find familiar areas in the home.
 - **Behavior.** A person may become easily confused, anxious, suspicious or fearful.
 - **Physical ability.** A person may have trouble with balance and use a walker or wheelchair to get around.
 - **Senses.** A person may experience changes in vision, hearing, sensitivity to temperature, or depth perception.

Care Goals

- Evaluate surroundings for any particular dangers and intervene to ensure safety at all times.
- Assess the person's ability to manage daily activities and be alert to any changes in condition.
- Monitor for caregiver strain or stress.

Recommended Practices

Home Environment

The home environment can support independence while promoting safety. A thorough home assessment by an occupational or physical therapist will identify potential problems and recommend solutions that improve care for people with dementia.

General Safety

- Ensure that the person does not have access to unsafe objects such as car keys, power tools, stove tops, guns, knives and scissors. Hide car keys, lock up equipment, remove stove top control knobs, and disable the garbage disposal.
- Hide or lock up cleaning supplies, medications and toxic items.
- Unplug electrical appliances when they are not in use.
- Disguise door handles and slide bolt locks at the top or bottom of exit doors to help prevent unsafe wandering. Motion sensors at exits can alert staff or a family caregiver that the person with dementia is near an exit door.
- For fire safety, ensure that the home has smoke alarms and a working fire extinguisher. Identify bedrooms with stickers for the fire department.
- Educate the person with dementia and family members about fire risks posed by the use of cigarettes, cigars, pipes, lighters and candles, especially when oxygen is being used in the home.



- Place emergency phone numbers at every telephone and keep a telephone and flashlight at the caregiver's bedside.
- Any change to the environment can cause confusion for the person with dementia, so the person, family and others familiar with the person need to be consulted before making any changes.

Fall and Accident Prevention

- Reduce glare on floors and remove rugs that a person could trip over.
- Remove obstacles from paths within the house, especially between the bed and the bathroom.
- Throw rugs and electrical cords and wires can be a hazard and cause falls.
- Ensure that lighting is bright and does not cast a glare on the floors. Keep nightlights in bedrooms, bathrooms, and hallways between the bedroom and bathroom.
- Place a sticker or tape a picture onto large plate glass windows so that a person with visual or spatial impairment does not run into them.

- Be sure that stairs have sturdy steps and hand rails. If stairs are carpeted, be sure carpet is firmly attached to every step. Steps can be highlighted with contrasting tape.

Bathroom Safety

- Ensure color contrast between the toilet, sink and bathtub and the rest of the bathroom.
- Place grab bars in the bathroom to help a person use the toilet and the bathtub.
- Shower benches, non-slip rubber mats, or self-stick strips on the floor of the tub or shower can help prevent falls. Replacing sliding shower doors with a shower curtain on a tension rod can help prevent the doors from popping out if the person with dementia uses them for support.
- Ensure that water faucet temperature is 110-120 degrees to prevent accidental burns.

Medication Safety

- Periodic medication reviews by a pharmacist or other qualified professional will identify and help eliminate poor use of medications, duplicate medications, negative drug interactions and incorrect dosage levels.
- In the early stages of dementia, a pill organizer can help a person take medications in the right amounts. The person can use a simple schedule to take medications at the right time.
- Set up the pill organizer for the person and regularly count medications to help ensure they are being used as prescribed.
- Ask the family caregiver where medications are kept and put all medications in one area. With permission, search the house for medications the family caregiver may have forgotten or the person may have hoarded.
- If the person cannot take medications without supervision, keep medications in a secure place. Do not leave pills out, and give them only when they are needed. It is important to make sure the person swallows the pills.

- Throw out all medications that are out of date or no longer in use. Providers should inform persons with dementia and their family members about proper disposal of unused medications that are leftover due to expiration, a change in treatment, or death of a person with dementia.
- Before a doctor visit, compile a list of medications and dosage amounts and bring it along at appointment time.
- Educate the person with dementia and family members about the potential dangers of combining alcohol, tobacco products, or other drugs with some medications.

Kitchen Safety

- Recommend appliances that have an auto shut-off feature and keep them away from water sources.
- Consider removing the knobs from stove burners.
- If necessary, turn off the gas or electric power to the stove.
- Remove vitamins, prescription drugs, sugar substitutes and seasonings from the kitchen table and counters.

Food Safety

- Ensure that basic food safety precautions are taken and that persons with dementia do not have access to foods that are harmful or not properly stored.
- Increase color contrast between food and plate, and plate and table to promote eating.

Guns and Firearms

- Keep firearms in a locked cabinet, safe, firearm vault or storage case, preferably outside of the living space.
- Lock ammunition in a place separate from firearms.
- Ask for help from the local sheriff or police if you are unfamiliar with firearm safety or choose to discard a weapon.
- Firearms should be unloaded when not in use.



5

End-of-life Care

Dementia Considerations

- Alzheimer's disease is a terminal illness with limited life expectancy.
- After receiving a diagnosis of dementia, a person needs to plan for the future, including end-of-life care. Planning, including the creation of an advance directive, should start as soon as possible because memory and the ability to communicate decisions decrease over time.
- While most persons with dementia die in a nursing home, a small percentage dies at home or in a hospital. Of those who die in hospitals, many are likely to transfer there from home as the result of an infection or health care crisis during the end stages of dementia. Others will die in assisted living residences, often using hospice services.

Care Goals

- Provide care that meets a person's changing needs, respects his or her choices about end-of-life care, and adapts to changes in care goals as a person's condition worsens.
- Culture plays a major role in both the person's and family's expectations about end-of-life care. It should be taken into account in any care planning.
- Minimize the person's physical, emotional and spiritual distress while maximizing comfort and well-being.
- Ensure open and ongoing communication, among the person, health care decision-maker, family and home care team, so that everyone knows the person's choices about end-of-life care and provides the best care.
- Support families when an individual is dying and after death by addressing their need for education about dementia and the dying process. Reassure them about the experiences the person with dementia has while dying.

Recommended Practices

Communication with Individuals and Family

- Excellent communication among the person with dementia (when appropriate), family caregiver, health care decision-maker and the broader care team is critical to end-of-life care that respects a person's choices.
- Communication differences can present problems for the person, family, and provider.
 - People and their families may require more time to communicate.
 - Short sentences, visual cues or pictures may help people with dementia understand what they are hearing.
 - Interpreters may be needed for people who do not speak English fluently. Use only a person's native language as dementia worsens.
 - Communication patterns vary among cultures.
- People with dementia who are dying of another disease may still be able to make choices about their care.
- People with severe dementia often communicate through their behaviors, including their reactions to care. Home care providers need to understand a person's behavioral symptoms and communicate with the person using methods that he or she can understand, such as gentle touch, direct eye contact, smiles and pleasant tone of voice.
- Decisions about end-of-life care are best made when those involved in decision-making understand dementia and what happens when people die of it, as well as the benefits and burdens of different types of care.
- People and their families also need education about hospice benefits under Medicare, Medicaid, and other insurance programs. If the person and family want hospice, encourage enrollment before

the person is close to death so that support acceptable to the person and family is in place well before death occurs.

TIMING OF COMMUNICATION

- Excellent communication about end-of-life care occurs among the person with dementia (when appropriate), health care decision-maker, family and broader care team, including the physician. Conversations need to respect the cultural background and spiritual beliefs of the person and family.
- Communication should continue as dementia gets worse so that everyone understands how a person's needs are changing and what these changes mean for care. Families and providers need to know the symptoms of active dying.
- Conversations about care decisions at the end-of-life can be difficult because of possible disagreements about medical treatments such as tube feeding.

EXAMPLE: Many family members fear that the person with dementia may be suffering from starvation when they no longer eat. Failure to eat can be a sign of dying, and persons with dementia generally are not uncomfortable during the final stages of the illness. Some treatments, like tube feeding, may have no benefit and may even cause harm. Everyone involved in decision-making needs to understand the possible effects of treatments so they can make informed decisions.

- Regular care planning meetings that involve the home care team as well as family members make communication about end-of-life care easier and help ensure that care changes as the person's condition does.
- Families of dying individuals need easy access to a home care team that responds to their needs and questions.
- If more than one provider is involved in care, then all providers, including hospice providers, need to communicate with one another and coordinate care.

- As the person's dementia gets worse, care goals may change from curing illness to comfort care and care plans may need to be adapted. Decisions should not be made without a recent assessment of the person's condition.
- If an authorized decision-maker decides on an aggressive or alternative medical intervention, or refuses treatment or care, the broader care team needs to make all feasible efforts to honor such a decision. However, the home care team is not required to deliver treatment or care that is determined to be medically inappropriate.
- If a decision is made to go against medical advice, families need to understand that the home care provider may refuse to provide services.

EXAMPLE: Home care providers may refuse to provide care if someone in the house is smoking while the person with dementia is on oxygen.

Assessment and Care for Physical Symptoms

Good end-of-life care for people with dementia ensures that people are treated for pain and other physical symptoms that may cause discomfort. When people cannot talk about their discomfort or providers cannot recognize it, problems can go untreated.

PROVIDER APPROACHES

- Providers need to regularly assess a person's physical symptoms and pain at the end of life to help prevent health problems.
EXAMPLE: Maintaining good mouth care, such as regular teeth brushing, can prevent tooth decay, mouth sores, and gum disease. These conditions can reduce food and fluid intake and cause health problems.
EXAMPLE: Good skin care reduces the risk for pressure ulcers.
- Direct care providers or family may be the first to notice a person's symptoms. Direct care providers need to recognize and communicate symptoms

to their supervisors or the home care team. Changes in behavior can be part of the dying process.

A checklist, which can include the following items, can help direct care providers note changes.

- ✓ Change in emotional health and well-being
- ✓ Yelling or calling out
- ✓ Restlessness
- ✓ Teeth grinding
- ✓ Movements that show distress
- ✓ Heavy breathing
- ✓ Changes in swallowing ability
- ✓ Loss of hunger and thirst
- ✓ Restless sleep
- ✓ Scratching or picking at skin or other body parts
- ✓ Changes in skin condition, such as bruises, open or discolored areas
- ✓ Sweating
- ✓ Dry mouth
- ✓ Drooling
- ✓ Bowel patterns and incontinence
- ✓ Signs of dying:
 - Decreased need for food and drink because body is slowing down
 - Difficulty swallowing
 - Increased sleep
 - Increased restlessness
 - Decreased urination
 - Moist-sounding breathing
 - Change in breathing patterns and difficulty breathing
 - Moaning sounds
 - Arms and legs may become cool to the touch and bluish in color
 - Fevers

- Individuals at the end of life often show few reactions or emotions. Sending the same direct care providers to serve a person will help them get to know the person, recognize and report any changes in condition, and meet his or her needs.
- Comfort care approaches to physical symptoms can be beneficial.
 - The use of oxygen or a fan that is aimed at the person can make breathing easier.
 - Positioning can be used to assist in decreasing pain or pressure areas.
 - A person's dry mouth can be moisturized by frequent cleaning or artificial saliva spray.
 - Difficulty with swallowing can be addressed by hands-on assistance with eating, changing food texture, or altering the consistency of liquids.
- NOTE: Syringe feeding is not an acceptable practice in most situations and should not be used for those with swallowing difficulties because it is unsafe.**
- Sometimes just holding the person's hand will provide some comfort when the source of distress is unknown. Careful observation and approach is important because some people are sensitive to touch at the end of life.
- Opioid medication can be used to effectively treat pain and breathing difficulty in some situations.

Assessment and Care for Behavioral Symptoms

ASSESSMENT

- At the end of life, behavior changes may show a person's distress, so finding the cause of changes is important. Direct care providers or family may be the first to notice these changes. Direct care providers need to be able to recognize the symptoms and communicate them to their supervisors or the home care team.

Using a checklist, which includes the following items, can make identification of behavioral symptoms easier.

- ✓ Changes in attention span and the ability to pay attention to the task
- ✓ Changes in alertness such as sleeping more, not responding to touch or sound
- ✓ Agitation
- ✓ Changes in mood
- ✓ Hallucinations
- ✓ Withdrawal from others
- ✓ Groaning or calling out
- ✓ Striking out or other physical movements

- The home care team needs to consider whether a person's behavior change may result from a known cause (e.g. drug effects), a change in health or emotional condition (e.g. pain or depression) that requires assessment and treatment, or is part of the natural dying process.

PROVIDER APPROACHES

- Dealing with the cause of the behavior comes first.
 - Using a medication, such as a sedative or antipsychotic, to sedate a person without treating the pain causing the behavior is inappropriate.
 - The use of antipsychotics or other psychotropic medications in consultation with a physician or pharmacist, who has expertise in their use, may

be helpful in calming a person who is very near death. At this point, the benefits and burdens of these medications are different than earlier in life when the risk of death may outweigh the benefit of using such medications.

- First try to address behaviors through care or environmental changes. These changes need to deal with unmet physical and emotional needs and reduce environmental irritants.
 - Use gentle care giving techniques including: telling the person what you are going to do before touching them or beginning care, apologizing for causing distress, and keeping the person covered and warm.
 - Make the environment calm and comfortable, such as playing soft music that a person likes, may help to minimize restlessness at the end of life.
 - Opioid medication may be prescribed when the person is actively dying to relieve pain or breathing difficulties.

Emotional and Spiritual Support of Individuals

- While the daily physical needs of individuals with dementia require care, their emotional and spiritual needs at the end of life are also important.
- People with dementia are able to find comfort in familiar and meaningful interactions with direct care providers, even if they are not able to respond.

EMOTIONAL SUPPORT

- Providing support to people dying of dementia involves everyone learning as much as possible about the person's life and choices about care and integrating these things into conversations during caregiving.
 - Encourage Spanish-speaking home care providers to speak that language with people whose first language is Spanish.
 - Play recorded violin music for a person who used to play this instrument.

SPIRITUAL SUPPORT

- Providers can give the best support when they know which spiritual practices are most important to the person. Family can provide this information.
- Providers who give palliative and hospice care have valuable expertise regarding the complicated emotional and spiritual support needs of individuals and families.

EMOTIONAL AND SPIRITUAL SUPPORT OF FAMILY

- Providers need to be able to recognize and respond to the needs of the person or family member who is grieving.
- Family members may experience grief beginning with diagnosis of dementia and continuing after death as caregiving ceases and feelings of loss escalate.
- Decision-makers may experience guilt when making end-of-life care choices for their loved ones. The home care team offers emotional and spiritual support for family throughout the grieving process.
- Family members may want support when a person is actively dying. A trained professional, such as a psychologist, social worker, faith leader, or nurse with dementia expertise, can help educate and guide the family through the person's dying process and ultimate death.
- Help families recognize the signs of dying so they can understand what their loved ones are experiencing.
- Provide respite for family caregivers who need time for themselves. They may want to attend religious services or caregiver support groups. A local hospice, the Area Agency on Aging or other community organization may offer respite services.

Family Participation in End-of-life Care

- Family members are an important part of the care team and generally want to care for and comfort their loved ones. Providers may give suggestions, like the ones below, to families members who want to participate in care:
 - Moisten the person's mouth
 - Massage the person's hands and feet
 - Play music that the person enjoys or read aloud from the person's favorite books
 - Use personal photos to share stories about family and friends
 - Provide the comfort of familiar objects
 - Talk to the person in a calm voice
 - Sit with the person so he or she is not alone
- Getting information from the decision-maker or family for the care plan affirms their central role in care and lets them know that they are helping their loved ones get better care.
- The agency can encourage family members to voice concerns and ask questions about end-of-life care to the home care team by providing an easy way to contact someone on the home care team 24 hours a day.
- Providers can refer families to the Alzheimer's Association or other caregiver support groups in the community.
- Hospice services can provide expert staff members who are skilled at meeting the needs of the person who is dying and family members who are mourning their loved ones. After a person's death, the family caregiver may need help to reconnect with old friends or resume old hobbies and activities.

6

Home Care Provider Training

- Providers who understand the symptoms of dementia (and how they differ from normal aging) are better able to provide good care.
- Direct care providers require education, supervision and support to ensure that the care they provide meets the needs of both the person with dementia and the family caregiver.
- Effective initial and ongoing training for all home care providers includes content in the following areas specific to dementia care:

The basics of good dementia care

- Alzheimer's disease and other types of dementia including the disease process, memory loss, behavioral symptoms, and end-of-life care
- Warning signs of dementia

Management of other medical conditions

- Presence of other conditions, such as diabetes and depression
- Identifying and addressing pain in persons with dementia
- Identifying and addressing other physical symptoms in persons with dementia

Communication with individuals and family

- Cognitive changes and communication challenges
- Approaches for effective communication

Understanding and addressing behaviors

- Ways to understand and relieve behavioral symptoms, including alternatives to restraints
- Non-pharmacological approaches to behavioral symptoms

Emotional and spiritual support of individuals and family

- Emotional reactions to dementia, such as grief
- Understanding of family relationships when coping with dementia

Person- and family-centered approaches to care

- Value of person-centered approaches to care and methods that are culturally sensitive
- Cultural differences surrounding care
- Importance of meaningful activities
- Techniques in promoting adequate food and fluid intake
- Staff approaches and environmental interventions specific to persons with dementia in all areas of care
- Involvement of family in all aspects of care including care planning and provision

Safety issues

- Safety issues and considerations for different situations such as working with someone who lives alone
- Home safety
- Medication safety and management
- Consequences of unsafe wandering
- Procedures to follow when a person is lost
- Risk assessment for falls including individual and environmental factors
- Understanding the benefits of physical activity and mobility
- Communication and coordination of care with other home care providers and other agencies

End-of-Life Care

- Communication and planning about end of life with people who have dementia and their families
- Respect for the treatment choices of decision-makers, even if they differ from the provider's personal beliefs
- Hospice and palliative care of persons with dementia
- Signs of impending death
- Awareness of and support for the family's grieving process
- Helping families get needed practical, emotional and spiritual support
- Grief experienced by home care providers when the condition of the person with dementia worsens or the person dies
- Supervisors may need coaching to help them support the direct care providers when they make decisions.

NOTE: Supervisors are important role models in providing good dementia care.

- Direct care providers need: recognition for their use of problem-solving approaches to providing care, emotional support as they deal with their own reactions to the declining health of individuals with dementia, and encouragement to get help from supervisors, or other members of the home care team, when needed.

7

Special Topics

Making the Most of a Home Visit

Providers need to understand safety issues as well as a person's specific needs when conducting a home visit.

- Schedule the first home visit at a time when a family caregiver will be available and that is best for the person with dementia (mornings are often a good time).
 - Learn about the person's daily routine and find a time when there is no regular activity scheduled.
- Upon arrival, introduce yourself and explain the purpose of your visit.
 - While in the person's home, treat him or her as a host or hostess and you will likely be treated as a guest.
- When entering, scan the room or house for any potential danger such as the presence of weapons.
- Approach persons with dementia from the front, address them by their preferred name, kneel or sit beside them in order to be at eye level. Be sure you have the person's attention before speaking.
- Request that the television be turned off or address any other environmental distraction.
- If the person becomes agitated, speak slowly and clearly in a calming voice. Focus on feelings, not facts.



Considerations for Those Who Live Alone

It is especially important to build rapport and develop effective communication with a person with dementia living alone. Frequently, individuals with dementia who live alone have a strong sense of independence, so building rapport may take time.

- People who live alone can be described by one of the following general categories:
 - They live alone but receive frequent support from relatives and friends living nearby.
 - They live alone with support from "long-distance" caregivers — usually adult children or siblings.
 - They have no close family members or friends to provide monitoring or assistance — this is the most vulnerable group.

NOTE: People with dementia who live alone are at high risk for self-neglect.

- 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 is suspicious, a call from the agency (to confirm that the provider is there to help) or from a family member (to verify that it is alright to let provider in) may be enough to gain entrance.
 - 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.
 - Build rapport by learning about the person's interests, history, favorite memories, family and friends.
 - Monitor food and fluid intake. If meals are being delivered, check to see that they are being eaten. Serve water and other liquids during visits. Dehydration is a serious risk.
 - Check for fire and other safety risks as part of every visit, including food left cooking on the stove, evidence of small fires, burns on the person or on furniture, and frayed or loose wires.

- Provide support to help the person with dementia maintain as much independence as possible.
- Anticipate and avoid crisis situations (See page 58 for more information on Emergency Preparedness.)

Clinical Medication Management

- Medications play a critical role in the overall treatment of the person with dementia, but they must be carefully managed. Medication side effects are often mistaken for the onset of new illnesses or aging itself. Recent literature supports the following general medication management guidelines:
 - A person with dementia should have an up-to-date medication list (including over-the-counter medications) that is available in his or her medical record and accessible to all healthcare providers. This will allow providers to identify potential medication-related causes of new symptoms, identify and eliminate inappropriate



duplication of therapies, correct dangerous interactions, and streamline the regimen to improve adherence.

- A person with dementia should have an annual medication regimen review.
- When a person with dementia is prescribed a new medication, the prescribed medication should have a clearly defined indication.
- A person with dementia and the family caregiver should receive appropriate education about the use of any new medication to improve adherence and clinical outcomes and to alert the person or caregiver to potential adverse effects.
- When a person is prescribed an ongoing medication for a chronic medical condition, response to therapy should be documented.

Transitions in Care

Family members and providers may not know when to ask for help or when to make changes to the care that the person with dementia is receiving. Providing good care means meeting the needs of the person — using one service or a combination of several services. Depending on the person's preferences, needs and abilities, it may be appropriate to look for different or more assistance.

In addition to an assessment of the person's medical and psychosocial needs, a functional assessment, including evaluation of the Activities of Daily Living (ADL) and the Instrumental Activities of Daily Living (IADL), must be completed to determine appropriate care options and services.

A transition of care is defined as moving from one practitioner or setting to another as condition and care needs change (Coleman and Boulton, 2003). It is usually accompanied by a change in care plan. This movement can take place within settings (e.g. within the home care team), between settings (e.g. between a hospital and home) and across health states (e.g. curative and palliative care).

To assess the need for a transition in care, consider the following questions:

- **Safety.** Is the person with dementia safe?
- **Health.** Is the health of the person with dementia, or the health of the caregiver, at risk?
- **Care needs.** Does the person with dementia need more care than he or she is receiving right now? Is caring for the person becoming more difficult for the primary care provider?

During transitions of care, communication — between the individual with dementia and his or her family, within the home care team, and among all providers involved in caring for the person — is especially important to ensure medication safety, understanding of the care plan, clarity of roles and responsibilities, and care coordination.

- When a person is discharged from the hospital or nursing home, the person with dementia (whenever possible) and the family caregiver need an opportunity to participate in the planning and know the reason for the discharge. At the time of discharge, the person with dementia and family caregiver need a clear understanding of the discharge plan and care instructions. In addition, the process of medication reconciliation should be performed in order to ensure that all medications are current, necessary and minimize the potential for drug interaction problems.

Elder Abuse and Neglect

Situations of abuse and neglect are some of the more difficult and complicated situations involving people with dementia. Persons with dementia may have difficulty speaking up about or noticing abusive or neglectful situations. It is important to use communication techniques to de-escalate the situation and to intervene appropriately, including making a report of the elder abuse or neglect.

- While one sign does not necessarily indicate abuse, some tell-tale signs that there could be a problem are:
 - Bruises, pressure marks, broken bones, abrasions, and burns may be an indication of physical abuse, neglect, or mistreatment.
 - Unexplained withdrawal from normal activities, a sudden change in alertness, and unusual depression may be indicators of emotional abuse.
 - Bruises around the breasts or genital area can occur from sexual abuse.
 - Sudden changes in financial situations may be the result of exploitation.
 - Pressure ulcers, unattended medical needs, poor hygiene, and unusual weight loss are indicators of possible neglect.
 - Behavior such as belittling, threats, and other uses of power and control by spouses are indicators of verbal or emotional abuse.
 - Strained or tense relationships and frequent arguments between the caregiver and elderly person are also signs.

- Sometimes persons with dementia neglect their own care, which can lead to illness or injury. Self-neglect can include behaviors or consequences such as:

- Hoarding
- Failure to take medications or get medical treatments when sick
- Poor hygiene and housekeeping
- Not wearing the right clothes for the weather
- Dehydration and malnourishment
- Eviction notices, failing to pay bills and utility shut offs

(National Center on Elder Abuse. Warning Signs of Elder Abuse and Self Neglect http://www.ncea.aoa.gov/NCEARoot/Main_Site/FAQ/Questions.aspx Accessed May 1, 2009.)

- Social workers are trained to assess for elder mistreatment, including self-neglect, and can help the home care team develop a plan to respond to such occurrences.
- Certain professionals have an ethical and legal responsibility to refer cases of suspected mistreatment to protective service agencies. Home care agencies often have guidelines regarding how to respond to abuse and neglect.
- All cases of abuse and neglect should be reported. Reports can be made to:
 - The National Adult Protective Services Association which will prepare a file for the abused or neglected individual. Each state has different contact centers. Visit <http://www.apsnetwork.org/> to find contact information for each of the 50 states.
 - The National Center on Elder Abuse can also be used to seek help regarding elder abuse and neglect. For state contact information, visit <http://www.ncea.aoa.gov/> or call 1-800-677-1116.



Caregiver Stress

No one with dementia remains at home safely without the help and support of family caregivers, who themselves can experience poor health and emotional issues as a result of their responsibilities. Providers can assess family caregivers to determine what type of support is needed. Responses to the following questions will help providers shape care for family caregivers:

- What is the family caregiver's health status?
- What are the caregiver's communication needs? For example, does the caregiver have hearing loss or need more time to respond? Communication with all caregivers should be clear and easily understood.
- What kind of help is the family caregiver providing, how often and for how long?
- What would the family caregiver like to continue doing? What would he or she like to stop doing? Is there any task that makes the caregiver feel unsafe or unqualified to handle?

- What support would the family caregiver like to have?
- What is the family caregiver's emotional status?
- What other responsibilities does the family caregiver have, such as child care and employment?

Travel Outside of the Home

Traveling outside of the home with a person who has dementia requires careful planning to ensure safety, comfort and enjoyment for everyone involved. Travel outside of the home may be necessary for medical appointments, social engagements or any variety of outings.

PLANNING THE VISIT

- Evaluate options for the best mode of travel based on needs, abilities, safety and preferences. Determine if an escort, in addition to the driver, may be needed for safe travel.
- When making a doctor's appointment, make every attempt to schedule the visit at a time when the office is least busy and a when the person's daily routine will be least disrupted.
- Communicate in advance with the people at the destination so they know this person has dementia.
- Try to visit places that were familiar before the onset of dementia.
- Keep travel as simple and manageable as possible; plan short trips and avoid multiple stops.
- Allow plenty of time for rest; do not over-schedule.



GETTING THERE

- At the time, talk to the person about the appointment or outing and respond to any questions he or she may have.
- Do not overload the person with too much information about the trip.
- Do not move too quickly or appear hurried.
 - Allow adequate time to get to your destination. Take into consideration parking, adequate accessibility, check-in procedures and any required paperwork.

DURING THE VISIT

- Remain with the person as much as possible to avoid wandering; call the doctor's office or other destination to arrange for someone to escort the person if a provider cannot.
- Tell the person when you cannot be with them and check in while you are away.

- Travel during the time of day that is best for the person with dementia. For example, if the late afternoon increases agitation, avoid traveling during this time.
- Avoid very loud destinations and places with a lot of people, especially if the person is overly tired.
- Have a bag of essential items at all times (e.g. medications, water, snacks and activity items). Make the person feel comfortable away from home; bring a photograph, favorite blanket or security object.
- Learn to recognize the signs of anxiety and agitation.

NOTE: Travel outside of the home presents a change in environment, and any change in environment for a person with dementia can trigger wandering behavior. Medic Alert® + Alzheimer's Association Safe Return® is essential for persons who are memory impaired and mobile. (See page 36 for more information on wandering and the Medic Alert® Alzheimer's Association Safe Return® program.)

Emergency Preparedness

Home care providers deal with emergencies, large and small, everyday. When people with dementia, who may already be scared or confused, are involved in an emergency situation, their response may be magnified or inappropriate. Strong communication skills may be the most important tool to keep the person safe from harm.

Some guidelines to use in the event of an emergency include:

- During initial visit, encourage family members to make an emergency kit. The kit should be kept in a watertight container and be easily accessible. It might include:
 - Easy on/off clothes (a couple sets)
 - Supplies of medication, or, at least, a list of medications with dosages
 - An extra pair of shoes or sneakers
 - A spare pair of eyeglasses

- Incontinence products
- Extra identification items
- Copies of legal documents, such as a power of attorney
- Copies of medical documents that indicate the individual's condition and current medications
- Copies of insurance and Social Security cards
- Physician's name, address and phone numbers (including cell phone)
- A recent picture of the person with dementia
- Hand lotion or other items to promote comfort
- Bottled water, favorite foods or liquid meals
- Pillow, toy or something else to hug; other favorite items
- Medic Alert® phone numbers
- Make sure any emergency plans include the individual's specific needs.
- Have a list of contact information for family or friends who might need to be reached in the event of an emergency or evacuation.
- Make sure people other than the primary caregiver have copies of the person with dementia's medical history, medications, physician information and family contacts.
- Emergency situations often include a change in environment, and this can lead to wandering (see page 36 for more information). Individuals should be enrolled in Medic Alert® + Alzheimer's Association Safe Return®.
- Make sure information is up to date with Medic Alert® + Alzheimer's Association Safe Return®.

EFFECTIVE COMMUNICATION STRATEGIES

- Use the "TALK" method for communicating:
 - **T**ake it slow — speak as slowly and calmly as you can.
 - **A**sk simple questions — single questions with one-word answers are most likely to be understood.
 - **L**imit "reality checks"— reasoning may not work.
 - **K**eep eye contact — non-verbal tactics, such as posture and eye contact, are key to successful communication.
- Remember that the individual has limited ability to understand directions and may forget them.
- Emergency situations may cause agitation, frustration, and feelings of being overwhelmed.
- During an emergency, remember to remain calm. People with dementia are especially vulnerable to chaos and emotional trauma; they will react to the provider's emotional response.

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 a client's condition progresses.

- Honor your grief when the person's condition changes or the person dies.
- Allow yourself time to do nothing.
- Participate in activities that you enjoy such as exercise, reading, watching movies or sports, or meditating.
- Nurture a sense of humor. Laughter heals the body and the mind.
- Set and maintain appropriate boundaries with the individuals and families you serve to avoid creating unrealistic expectations and prevent burnout.
 - Avoid sharing your home phone number or other personal 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 home 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 other members of your team.
- Seek professional support 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 family caregivers do. Your ability to continue serving them well depends on your ability to take care of yourself.

8

Glossary

Active Dying means that a person's bodily systems are failing. Skin color and feel may change and arms and legs may get cooler to the touch. The person may not respond to others, eat or drink. Death will likely occur in hours or days.

Activity refers to the interaction between an individual and his or her physical, social and cultural environments. Activities are limitless. Every interaction, event, encounter, and exchange is considered an activity. Activities give meaning to life, help to structure the day, give a sense of accomplishment, and help a person feel valued.

- *Meaningful Activity*: Activities are meaningful when they reflect a person's interests and lifestyle, are enjoyable to the person, help the person feel useful, and provide a sense of belonging.

Activities of Daily Living (ADLs) are activities related to personal care and include bathing or showering, dressing, getting in or out of bed or a chair, walking, using the toilet, and eating.

Adult Day Care provides care outside the home and is designed to meet a person's needs while supporting strengths, abilities and independence.

Adult Protective Services is responsible for investigating abuse, neglect, and exploitation of adults who are elderly or have disabilities.

Advance Directives are legal papers that document the person's choices for health care treatments and end-of-life care. A *living will* states the person's choices about medical treatments. A *durable power of attorney for health care* (also known as *health care agent* or *health care proxy*) states who will make medical treatment decisions for a person when he or she cannot.

Area Agencies on Aging (AAAs) were established under the Older Americans Act (OAA) in 1973 to respond to the needs of Americans age 60 and over in every local community. AAAs provide a range of home and community-based services. (National Association of Area Agencies on Aging, 2009)

Care Management is a service that provides assistance for families in assessing the needs of older adults and making arrangements for services to help them remain as independent as possible. The service also helps individuals and families coordinate care.

Care Team means the group of people who work together to plan and carry out a person's care plan. The team may include the person, family members, health care decision-maker, and home care providers involved in care as well as those who provide spiritual support.

Cultural Competence includes awareness of the home care providers' own cultural values and beliefs; knowledge and understanding of the history, traditions, and values of the person with dementia and his or her family; and skills in working with people of different cultures.

Delusion is a strongly-held belief that is not true. Delusions can cause people with dementia to think that someone is going to harm, steal or be unfaithful to them. Delusions can make a person with dementia harm a caregiver.

End-of-life Care means care that focuses on comforting the person and includes provision of palliative or hospice services before death. The length of time before death that is considered "end of life" varies for each person and is hard to predict.

Family includes people who may or may not be related to a person, but who play a major role in the person's life, such as a best friend.

Geriatric Care Manager is a professional who provides care management services to older adults. (See definition for *Care Management*.)

Hallucination occurs when a person sees or hears things that are not there.

Health Literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Home Modification includes adapting the home to increase the ease of use, safety, security and independence in the home.

Home Care Team may include the following providers:

- *Audiologists* help evaluate and manage hearing and balance disorders.
- *Certified Nursing Assistants* help people with all activities of daily living and related care.
- *Chaplains* attend to the spiritual care of the person with dementia and family caregivers as an integral part of the support provided by the hospice team. The chaplain, trained and credentialed to provide care in ways which are respectful of each person's spiritual traditions, may serve as the primary pastoral support, or may, at the family's request, assist them in connecting to a faith community leader of their own tradition.
- *Companions* generally spend time with the person to help him or her to remain safe and have a social life.
- *Home Health Aides* provide supports similar to those given by personal care aides, but have a minimum of 75 hours of training and perform health-related tasks such as monitoring vital signs, assistance with taking medications and range-of-motion exercises. Home health aides are required for Medicare-certified home care plans that include aide services.
- *Homemakers* help people with activities like making meals, cleaning house and shopping.
- *Licensed Practical Nurses (LPNs) and Licensed Vocational Nurses (LVNs)* perform certain skilled services in the home setting such as vital signs, injections, wound care, and basic assessment. Individual states restrict medication administration of certain drugs based on the nurse's credentials.
- *Occupational Therapists* help individuals maximize independence in daily activities (occupations) that the individual needs or wants to do. Practitioners evaluate and recommend changes for the individual and adaptations to his or her environment to accommodate the effects of the disease and to improve safety and functional capability.
- *Personal Care Aide / Home Care Aides* allow individuals to remain in their homes and communities by providing assistance with Activities of Daily Living (ADLs) such as bathing, dressing and eating, and Instrumental Activities of Daily Living (IADLs) such as shopping and light housekeeping.
- *Pharmacists* are medication therapy experts who, in conjunction with other home care team members, ensure that the person's medications are the most appropriate, the most effective and the most safe and that they are used correctly. Clinical responsibility includes the resolution and prevention of medication-related problems that may interfere with the goals of therapy.
- *Physical Therapists* diagnose and treat individuals of all ages who have medical problems or other health-related conditions that limit their ability to move and perform functional activities in their daily lives. Physical Therapists examine each individual and develop a plan using treatment techniques to promote the ability to move, reduce pain, restore function, prevent disability and promote wellness.

- *Physicians* diagnose and treat illnesses as well as oversee the management of all of the person's medical conditions.
- *Psychologists* evaluate and treat mental health problems, including disturbances in cognitive (thinking), emotional, and behavioral functioning.
- *Registered Dietitians* provide a professional nutrition assessment and make recommendations for nutrition intervention.
- *Registered Nurses (RNs)* perform some of the same skilled nursing services as LPNs and LVNs in the home setting, but also provide disease management education, more comprehensive clinical assessment, planning and care coordination. Registered nurses conduct admission and discharge assessments.
- *Speech-Language Pathologists (SLPs)* assess, diagnose, and treat people with speech, language, cognitive-communication, and swallowing disorders. SLPs also screen hearing and evaluate each person in his or her living environment to promote communication well-being.
- *Social Workers* assess the social and emotional factors affecting individuals' and families' health and well-being, diagnose and treat mental health problems, and help people locate and use services.
- *Volunteers* may be able to provide assistance with companionship, transportation, friendly visits and emotional support.

Home Care includes a wide range of health and social services that are delivered at home to people in need of medical, nursing, social, and therapeutic treatment, or assistance with daily activities such as bathing, dressing, toileting, and household chores. Services can be provided wherever the person with dementia resides — their house or apartment, independent living community, or assisted living residence.

Home Health Agencies offer a variety of skilled and supportive services.

Home Repair includes services that help keep housing in good repair, such as roofing, plumbing and insulation.

Hospice Care in the United States is palliative care for individuals who are dying and expected to live six months or less. Hospice care involves an interdisciplinary team of skilled staff and volunteers who provide comprehensive medical, psychological, and spiritual care for people who are terminally ill as well as support for these persons' families. This care also includes the provision of related medications, medical supplies and equipment.

NOTE: Hospice is a Medicare benefit available in most state Medicaid programs and many private health insurance plans. The federal Department of Veterans Affairs has a home hospice benefit that may be available to veterans, even if they have not used the Department's health system in the past.

Instrumental Activities of Daily Living (IADLs) are activities related to independent living and include preparing meals, managing money or medications, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

Medication Reconciliation is the process of comparing a patient's medication orders to all of the medications that the patient has been taking. This process helps identify medication errors such as omissions, duplications, dosing errors, or drug interactions.

Nutrition Services include home-delivered meals (e.g. Meals on Wheels) for persons who cannot leave home or prepare their own meals as well as congregate meals in a senior center or other site where older adults can enjoy a meal and socialize with others.

Palliative Care is designed to alleviate physical, emotional and spiritual suffering and enhance a resident's quality of life, rather than cure a disease or medical condition. Palliative care focuses on providing comfort to a suffering individual and his or her family. People who receive palliative care may or may not be terminally ill and do not have to forego curative treatment.

Private-Duty Agencies generally provide individuals with nursing, homemaker, home care aide, and companion services.

Registries are employment agencies for nurses and aides that match these providers with clients and collect finder's fees.

Respite Care provides the family caregiver with a break from their daily responsibilities. It can be for a few hours, several days, or weeks, depending on needs and interests. Respite care can be provided at home, at an adult day center or in another care setting.

Senior Centers provide a wide array of services, including nutrition, recreation, health education and fitness activities.

Spiritual Support means care that helps individuals and their families find meaning and comfort at the end of life that is consistent with their philosophical or religious values or outlook on life.

Telephone Reassurance involves trained volunteers who check in with persons who are socially isolated to see how they are doing.

Transition of Care describes the changes that individuals and families experience when a person with an illness, disability, or injury transitions from one health care provider to another or from one place to another, such as from home to hospital, or rehabilitation center to home. It can also describe shifts in an individual's health condition, such as when she or he goes from home health (rehabilitative treatment) to hospice care.

Transportation Services are available in many communities through aging services programs, regional mass transportation systems and private sources. These services may include door-to-door taxicab services, public bus transportation, or vans with wheelchair-accessible transportation.

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