



Wisconsin Alzheimer's Institute

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



Home Health Guide

Information for Home Health Clinicians

A comprehensive guide for home health clinicians to train caregivers on how to prevent, identify, and manage the medical issues commonly associated with moderate to severe dementia

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User Guide

Introduction

This Clinician Manual was developed by the Wisconsin Alzheimer's Institute in partnership with Chartwell Midwest Wisconsin Home Health Agency (formerly UW Home Health). The audience for this manual is home health clinicians. There is a companion manual designed for caregivers of people with moderate to severe dementia living at home, the Caregiver Manual. These manuals were developed as part of a project to enable people with dementia to live at home for as long as possible. The Clinician Manual is meant to serve as a tool to empower clinicians to treat and support the individual with dementia and to train caregivers to handle common medical concerns associated with the later stages of dementia. The goal is to avoid hospitalizations or emergency room visits by managing common medical complications of dementia by:

- Preventing common medical complications
- Identifying a problem early
- Managing the problem
- Recognizing when a treatment is not working and seeking help early, prior to an unplanned hospitalization or emergency department visit

Clinician Manual

Each module in the Clinician Manual corresponds to a module in the Caregiver Manual. The modules in the Clinician Manual provide a brief evidence-informed synopsis of medical problems associated with moderate to severe dementia, as well as care plan goals related to providing education on that topic for the caregiver. It is recommended that the home health clinician review the Clinician Manual module before providing education to the caregiver on each topic.

Objectives for the Training Manual:

1. Increase home health clinician knowledge about the medical complications of moderate to severe dementia
2. Increase home health clinician self-efficacy to train caregivers of individuals with moderate to severe dementia

Caregiver Manual

The Caregiver Manual is a teaching tool and resource for caregivers. Each module includes information for caregivers, as well as teach back questions for the nurse to assess the learner's understanding of the material.

Objectives for the Caregiver Manual:

1. Increase caregiver confidence to handle common medical problems associated with dementia
2. Decrease caregiver burden and stress
3. Reduce unplanned hospitalizations or emergency department visits

How to Use the Manuals

Both manuals include a table of contents that serves as a checklist. The goal is to review each module with the caregiver over the course of the home health episode. Each caregiver will have different needs. Some topics will be more pressing than others. For example, if the individual with dementia was discharged from the hospital with an aspiration pneumonia diagnosis, the modules on swallowing problems and pneumonia may be more important to the caregiver than the module addressing constipation.

The modules Dementia Basics, Caregiver Role Strain, and Resources—Getting Help should be completed at the start of the caregiver training. After that, the modules can be reviewed and taught in any order. The topics of the modules were chosen because they are all common medical complications for persons with moderate to severe dementia. Even if the health condition is not a problem now, it could become one in the future, especially as the disease progresses. It is important to inform caregivers that there is a risk to develop this problem, and that there are tools to prevent it – or identify and manage the problem should it occur.

In the first caregiver training visit, go through the table of contents with the caregiver to identify those problems that are currently a concern. Try to touch on all the topics over the course of your home health encounter, but it is appropriate to prioritize those problems that are of biggest concern to the caregiver.

The training is appropriate for any caregiver. If there are alternate or paid caregivers in the home, it is important to involve them in the training as well. When involving paid caregivers, you may choose to prioritize the modules that have to do with direct caregiving. For example, it would be important for a paid caregiver who assists with bathing to hear information about preventing and identifying pressure injuries. As you work through the modules, check off on the teach back forms when they have been completed and who received the education.



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Dementia Basics

Dementia is not a specific disease, but a syndrome or cluster of symptoms, defined by having deficits in 2 or more cognitive areas and a significant decline in previous abilities. Dementia interferes with a person's ability to carry out instrumental activities of daily living (IADLs). In order to be called dementia, this cluster of symptoms cannot be explained by another condition¹. Alzheimer's disease (AD) is the most common cause of dementia, accounting for between 60 and 80% of cases. Alzheimer's disease is a progressive, neurodegenerative disorder. It is the 6th leading cause of death in the United States². Vascular dementia is associated with cardiovascular disease, and may be due to a stroke or chronic microvascular damage to the brain. Vascular dementia may co-exist with AD or other dementias. Other forms of dementia include Lewy body dementia, Fronto-temporal dementia, and Parkinson's disease dementia. Although there are different causes of dementia, people living with the syndrome are at risk for a common set of medical complications. The purpose of these modules is to help prevent, identify, and manage the medical complications of moderate to severe dementia among individuals living in the community, with the overarching goal of preventing unplanned emergency department visits or hospitalizations.

There are other conditions that cause symptoms that mimic dementia such as mild cognitive impairment (MCI) and delirium. Dementia primarily affects the cognitive domains of attention, executive function, memory and learning; language, visual-perceptual, and social cognition¹. An individual with MCI may have mild deficits in one or more of these cognitive domains, but the cognitive decline is mild enough to not cause any functional deficits. Some people with MCI will go on to develop dementia, but some will not³. Delirium is a clinical syndrome characterized by inattention and cognitive dysfunction. Delirium occurs in the setting of a medical condition and is transient, reversible, acute, and fluctuating⁴. In contrast, dementia develops gradually and is irreversible. Older adults are at high risk for delirium during a hospital stay. Among older adults, the highest risk factor for delirium is dementia⁴. Therefore, it is not uncommon for an older adult to be discharged from the hospital with delirium superimposed on dementia. Delirium may take weeks to dissipate, and even then the individual with dementia may never return to pre-delirium levels of functioning.

Assessment

Dementia is classified by stages. How quickly an individual living with dementia will move through the stages is dependent on multiple factors including the underlying cause of the dementia and comorbid conditions including other chronic diseases or psychiatric illnesses⁵. The moderate stage of dementia is characterized by deteriorating cognitive abilities, increasing memory impairment, and a decline in functioning. Often the individual will need assistance with bathing and dressing and will often have impairment with mobility. In this stage, behavioral and psychological symptoms of dementia (BPSD) emerge or progress⁵. The severe stage of dementia is characterized by profound cognitive and memory impairment, difficulty communicating, incontinence of bladder and bowel and the inability to ambulate independently⁵.

The Quick Dementia Rating System (QDRS) is a rapid dementia staging tool⁶. On its own, the QDRS should not be used to diagnose dementia. However, it is a valid and reliable tool to determine if a problem is present, and if present, how severe the problem is⁶. For the purposes of home health, the QDRS is used to identify which clients might benefit from services such as a personal care worker, meal preparation services, or palliative care. We want to be sure that we are offering the education to caregivers whose loved ones are in the moderate to severe stages of dementia, because that is when medical complications ensue. The QDRS should be completed with the help of a caregiver who can give reliable information about the extent and severity of a change from prior abilities⁶. When asking the caregiver to rate the change in the person's ability, emphasize changes due to cognitive problems. If there are physical limitations, ask the caregiver to rate whether the person could perform a task if the physical limitation was not present⁶. The QDRS is scored on a scale from 0-30, with a higher score indicating more impairment. The QDRS scores are categorized as follows:

- Normal 0-1
- Mild cognitive impairment 2-5
- Mild dementia 6-12
- Moderate dementia 13-20
- Severe dementia 20-30

For individuals who fall in the normal range, the likelihood of dementia is small, yet a very early disease process cannot be ruled out⁶. Determining the stage of dementia is also important for determining treatment and management strategies.

Treatment

The underlying cause of dementia determines the treatment strategy. Although medications can play a role in the treatment of dementia, non-pharmacological interventions are likely to have the biggest impact for both clients and caregivers. Any treatment plan should be tailored to the client with dementia and involve caregivers. The health care team includes medicine, social work, pharmacy, physical therapy, occupational therapy, nursing, and speech therapy. Depending on the person, pastoral care may also be a key aspect of the plan. Dementia is a progressive disease, so it is important to constantly reassess the management plan and make adjustments as needed.

A sudden decline in cognition or change in behavior is most likely due to a medical problem. Many times these medical problems are treatable, such as a urinary tract infection or constipation. Assessing and intervening early can be the key to preventing unplanned health care visits and hospitalizations.

Care Plan Goals

1. Caregiver will describe two characteristics of moderate stage dementia.
2. Caregiver will describe two characteristics of severe stage dementia.
3. Caregiver will explain how a hospitalization may be harmful to the person with dementia.
4. Caregiver will explain what to do when there is a sudden change (worsening) in cognition or dementia-related behavior.

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Provided by ACT on Alzheimer's: Alzheimer's Disease Curriculum: Module X—Caregiver Support

Caregiver Role Strain

Caregiving is a term that generally encompasses extraordinary care that exceeds the bounds of what is usually considered typical responsibilities for others^{1,2}. This includes helping with one or more activities of daily living (ADLs), including dressing, bathing, toileting, and feeding. It also includes providing help with instrumental activities of daily living (IADLs), such as shopping, meal preparation, transportation, medication management, and managing finances. In addition, caregiving includes providing emotional support, and case management². Caregivers of individuals with dementia are more heavily involved with ADLs and IADLs and dedicate more time to these responsibilities^{2,3,4}. Caregivers of those with dementia also face increased emotional and psychological challenges given that the individual they are caring for, usually a loved one, often loses the ability to recognize the caregiver and can exhibit challenging behaviors as a part of the disease process^{2,3}.

There are many risks associated with caregiving for individuals with dementia including physical, social, psychological, and financial risks.

Physical risks – Caregivers have less time to rest when sick, less time to exercise, and less time to get adequate rest. Caregivers are less likely to engage in preventive health behaviors and have a greater prevalence of chronic illnesses and higher mortality risk than non-caregivers. They are also at risk for injuries from moving and positioning a person who depends on them for help with self-care and mobility.

Social risks – Caregiving can be an isolating experience, and caregivers often have to give up social activities due to caregiving responsibilities. Caregivers experience higher rates of conflict among family members and higher rates of spousal conflict.

Psychological risks – Caregivers are at higher risk for stress, anxiety, fatigue, insomnia, and depression than non-caregivers. This is particularly true for female caregivers.

Financial risks – Some of the financial sacrifices caregivers make include work adjustments, retiring early, losing job benefits, going to work late or leaving early, and taking time off to provide care. Further, due to the physical and psychological risks of caregiving, caregivers have increased costs due to their own health issues.

Assessment

Gathering information to identify caregiver needs, resources, and strengths is critical for determining appropriate goals and matching interventions most appropriate for the caregiver in achieving the desired goals. It is important to individualize treatment or care to the aspects of caregiving that are most troubling to a particular caregiver. This information is gathered in the “Resources – Getting Help” module. Your agency may use a particular caregiver stress assessment. Some commonly used include:

- Zarit Burden Inventory⁵
- Caregiver Strain Index⁶

It is advised that the social worker interprets scores on these assessments and develops an intervention plan for caregivers whose scores indicate high burden. Even those caregivers not currently experiencing a high degree of role strain at this time are at risk for role strain in the future due to the progressive nature of the disease. It is important to raise awareness of resources early, so if the stress of caregiving increases rapidly, the caregiver can mobilize those resources. For example, the burden of caregiving may increase dramatically when the person with dementia or caregiver becomes ill.

Care Plan Goals

1. Caregiver will describe role strain.
2. Caregiver will name two ways to reduce caregiver strain.
3. Caregiver will identify resources for extra help in times of crisis.

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Falls

Information for Home Health Clinicians

Falls

The risk of falling among individuals with moderate to severe dementia is twice that of older adults with normal cognition. Falls are a major cause of morbidity and mortality among all older adults, but individuals with dementia are more likely to have a serious consequence from a fall. Compared to individuals without dementia who fall, people with dementia who fall are five times more likely to be admitted to long-term care. They are also more likely to have injuries associated with high mortality, such as hip fractures and head trauma¹. Falls are associated with emergency department visits and hospitalizations even when there is not a fracture. The risk factors for falls among individuals with dementia can be either disease-related or environmental. Disease-related risk factors will vary significantly based on the stage of dementia and comorbid conditions (e.g., diabetes, anemia, spinal stenosis, neuropathy, vision impairment, muscle weakness, and foot problems). Individuals with dementia may be more likely to fall than other older adults due to visual-spatial impairments, gait disorders, inability to recognize or avoid hazards, medications, and other causes. The home environment is also key to the safety and fall risk of people with dementia.

Prevention

Fall prevention interventions designed for older adults with normal cognition are not as effective in individuals with dementia¹. Studies of interventions to prevent falls in individuals with dementia are sparse and largely inconclusive². There are many interventions shown to prevent falls in older adults living in their homes³. The most effective approach to preventing falls is likely a multi-factorial intervention tailored to the individual that includes multiple disciplines, including the primary care provider, physical therapy, occupational therapy, and nursing. Some effective interventions to reduce the risk or rate of falls are:

- Home safety assessments and modifications, especially when performed by a occupational therapist³
- Progressive balance and strength exercise programs³
- Cataract surgery in individuals with cataracts
- Gradual withdrawal of psychotropic medications (e.g., anxiolytics, antipsychotics, antidepressants, sedative hypnotics)
- Vitamin D supplementation if an individual is deficient in Vitamin D
- Pacemakers in people with carotid sinus hypersensitivity

Physiologic and Cognitive Changes

Many changes that co-occur as dementia progresses increase a person's risk for falling, so changes in these areas should be noted as part of a multi-factorial fall prevention assessment. These are covered in greater detail in other modules in this manual, and include:

- Incontinence (see Incontinence)
- Behavior, mood, and affect changes (see Behavioral Changes)
- Communication deficits (see Communication Changes)
- Advancing cognitive decline affecting insight, situational orientation, and problem-solving (see Dementia Basics)

Home Environment

An assessment of the structural barriers and affordances in the home are effective at reducing falls and risk of falls in people with dementia. Occupational therapists may do this through an occupational profile interview with the caregiver or with an observational checklist^{4,5,6}. They can then tailor modifications or equipment to reduce fall risks and enhance strengths so the person with dementia can do their best and find daily routines pleasurable⁷. This approach includes:

- Assessing person's performance of self-care, start/end-of-day routines, and bathroom tasks, which are common places, times, and occupations for falls
- Observing balance during activities of daily living and document observations in a performance-based tool such as the Tinetti balance scale⁸
- Removing floor and hallway clutter, such as storage, furniture, or area rugs
- Suggesting adequate and appropriate lighting
- Arranging items such as a commode or water glass in the person's line of sight
- Recommending durable medical equipment for daily routines that help the person move more easily and reduce lifting for the caregiver, such as bathroom grab bars, tub transfer equipment, and places for them to rest while moving about the home

Movement and Gait

Physical therapists are experts in motor performance, which often becomes impaired in moderate to severe Alzheimer's due to changes in neuro-motor control and sensory feedback. Physical therapists can help people with dementia avoid falls by treating balance and strength changes, and keeping people moving and active in their communities and homes^{9,10}. New evidence is showing that exercise appears to slow the development of impairments and symptoms in person with dementia^{11,12}. The following are included in the assessment and treatment of movement and gait impairments:

- Assess the interest and ability of the person with dementia and caregiver to participate in a home exercise program
- Assess strength, sensation, proprioception, balance, and gait
- Assess footwear
- Monitor pain and biomechanics during gait and transfers
- Develop and teach a home exercise program targeting balance and lower body strength that is appropriate for the person with dementia and can be supervised by their caregiver
- Introduce mobility device such as a walker, cane, or wheelchair, if the person is agreeable and the therapist determines they can use them safely. This may be paired with other interventions, because acquiring new skills is challenging in moderate to severe dementia due to impaired learning
- Coach the caregiver in ways to help the person with dementia move safely throughout the day

Visuospatial Processing Changes

In addition to typical age-related vision changes, many people with dementia experience difficulty using visual information to understand and respond to the world. This includes recognizing, handling, and appropriately using familiar objects and environments, perceiving items accurately (e.g., trying to water the plants with a hairbrush), and recognizing hazards in their path. If spatial planning is predominantly affected, the person may know they are holding a fork at their meal, but be unsure of how to use it. This is due to damage caused by advancing disease in the visual and spatial processing areas of the brain. This cannot be reversed, but its effect on fall risk can be decreased through adaptive interventions.

An occupational therapist can assess the impact that the person's visuospatial function has on his or her performance of daily activities, and recommend adaptations appropriate to his or her ability. Specific assessments include:

- Review of vision prescription if the person wears multi-focal lenses, and collaborate with the prescriber to discuss the benefits and risks of constant wear of multi-focal lenses for a person with dementia
- Observation of the person's interaction with familiar and novel objects during activities of daily living to determine an asset-based picture of visual processing
- Asking the caregiver if they observe the person squinting, tilting their head, stumble or bump things when moving around, or rub or blink their eyes
- Giving multi-sensory cues for the person who seems to be forgetting what to do with familiar objects. For instance if he or she *hears* what an item is while *looking* at it, do he or she use it appropriately?
- Arranging space and task items to compensate for visuospatial deficits and give cues to limit wandering, such as checkered mats in front of doors¹³

Medications

Most older adults take multiple medications, any of which has about an equal chance of doing good as causing harm. There are some medications known to contribute to the risk of falls. The benefits of taking any given medication can outweigh the harms. However, consideration should be given to any of the medications listed below in relation to their contribution to fall risk.

Other medication classes have been shown to contribute to falls. Take note of any medications started or with an increase in dosage shortly before a fall, as the new medication is a likely cause or contributing factor. Antihypertensive medications, diuretics,

Class	Examples
Benzodiazepines	lorazepam, clonazepam, alprazolam, diazepam
Tricyclic antidepressants	amitriptyline, nortriptyline, doxepin
Neuroleptics and antipsychotics	risperidone, quetiapine, olanzapine, clozapine
Anticholinergic medications	antihistamines (e.g., diphenhydramine, hydroxyzine, meclizine); antimuscarinics (e.g., oxybutynin, tolterodine); skeletal muscle relaxants (e.g., cyclobenzaprine)

and beta blockers can cause low blood pressure or lightheadedness with standing. Narcotic medications can also increase the likelihood of falls due to sedation. In general, the risk of falls with any medication is dose related. Individuals with dementia who fall may be able to have the dose of a medication reduced, especially if the condition the medication is treating is stable.

Assessment

The history of what happened prior to the fall is key to determining the underlying cause. In a person with moderate to severe dementia, the caregiver or a witness will need to provide the history or corroborate the person's report of the fall. Symptoms at the time of the fall can point to reversible causes. For example, a sudden visual loss or unilateral extremity weakness indicates stroke.

The history may be difficult to gather, especially if the fall was not witnessed. It is key to do a thorough physical assessment. The exam should be tailored to the individual client but also include:

- Orthostatic vital signs
- Cardiovascular system
- Musculoskeletal system
- Neurologic system
- Visuo-perceptual system
- Mood and affect

If there is a fall, or a new cluster of falls, the person should be assessed by a primary care provider as the falls can indicate an underlying illness. A provider visit is also warranted if the fall is accompanied by weakness, worsening confusion, or symptoms of an acute illness.

Care Plan Goals

1. Caregiver will identify two risk factors for falls in the care recipient.
2. Caregiver will name two ways to prevent falls in the home.
3. Caregiver will describe how to manage a fall in the home.

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What is a Pressure Injury?

In April, 2016, the National Pressure Ulcer Advisory Council (NPUAP) announced that the term “pressure injury” will replace the term “pressure ulcer.” According to the NPUAP:

A pressure injury is localized damage to the skin and/or underlying soft tissue usually over a bony prominence or related to a medical or other device. The injury can present as intact skin or an open ulcer and may be painful. The injury occurs as a result of intense and/or prolonged pressure or pressure in combination with shear. The tolerance of soft tissue for pressure and shear may also be affected by microclimate, nutrition, perfusion, co-morbidities and condition of the soft tissue².

Pressure injuries are also known as decubitus ulcers or bed sores.

Pressure injuries are a common complication of advanced dementia, with a prevalence between 39 and 47%¹. Individuals with dementia are at an increased risk for pressure injuries for several reasons. Dementia affects the motor neuron pathway, leading to gait disorders, falls, weakness, and immobility. Malnutrition associated with dementia contributes to the risk for skin breakdown. Sensory deficits are common in dementia which could make it difficult to sense certain textures, weight, or pressure. Furthermore, individuals in the late stages may have a diminished pain response. Blood pressure dysregulation can lead to hypotension and poor peripheral perfusion, increasing the risk of pressure injury¹. There is a higher incidence of incontinence among individuals with dementia and due to communication difficulties, wet clothing and products may stay longer on the skin. As cognition and functional abilities decline, the likelihood of a pressure injury increases.

Prevention

The home health clinicians are key to the prevention of pressure injuries in individuals with moderate to severe dementia living at home. Two key areas of responsibility are to 1) mobilize the interdisciplinary team for at-risk individuals with dementia and 2) provide caregiver education on how to prevent skin injury. A teaching tool is provided in the Caregiver Manual. An interdisciplinary team approach to preventing pressure injuries includes:

- Occupational therapy and physical therapy addressing mobility issues through interventions for
 - Maintaining strength and functional mobility through a daily routine that includes frequent movement
 - Teaching caregivers how to safely transfer the person with dementia, including use and training of moving devices
 - Assess, recommend, and train caregivers to use specialty beds or mattresses as the individual moves less
- Nursing for skin care, incontinence management, and nutrition
 - May discuss incontinence management options or a dietary consult with the primary care provider
- Speech therapy for individuals with dysphagia
- Social work for advocating for a personal care assistant to help with bathing, dressing, toileting, and repositioning, and assessing the caregiver’s perspectives and needs around pressure injury prevention

Assessment

All clients should be assessed regularly for risk of pressure injury with a standardized tool, such as the Braden or Norton. In addition to a risk assessment tool, home clinicians should evaluate the supports in place in the home to prevent and manage pressure injuries. This includes caregiver readiness and ability to prevent and manage pressure injuries. Caregivers should be taught to check the skin regularly.

If a pressure injury is present, document according to your agency's guidelines. There is standard nomenclature for pressure injuries as defined by the NPUAP². These definitions can be found at <http://www.npuap.org/>. If a wound is not healing as expected, consider medical complications and treatment failure. It may also be a sign that the caregiver is having difficulty managing skin and wound care.

Management

Frequently, nurses become the experts in pressure injury management. Many primary care providers rely on nurses to recommend treatments. In determining a treatment regimen, it is important to partner with the primary care provider and family to determine the goals of care. In end-stage dementia, the goal of wound care is usually not to heal the pressure injury, but to prevent deterioration while maintaining comfort and quality of life. For pressure injuries not healing as expected, consider a wound and ostomy nurse consult.

Occupational therapy and physical therapy help caregivers manage pressure injury risk and healing through:

- Training caregivers in safe transfer techniques and devices, including safe moving equipment
- Assessing seating and positioning, educating caregivers on sleep positioning to protect bony prominences, and ordering or recommending specialized cushions or mattresses
- Instructing caregivers in assessing skin integrity and protecting soft tissue during seated daily self-care routines that involve a high risk of shearing force, such as toileting and bathing
- Creating a person/family-centered movement plan that works with the family's routines to help the person shift weight several times per hour; may include putting on music to "dance," moving the person's seating device relative to a point of attention (e.g., the window, the TV), and walking with assistance to the bathroom, dining area, etc.
- Using calming or distracting strategies to decrease agitation and related repetitive movements

Care Plan Goals

1. Caregiver will name two ways to prevent pressure injuries.
2. Caregiver will describe two characteristics of a pressure injury.
3. Caregiver will describe one way to manage a pressure injury.
4. Caregiver will name two signs of an injected pressure injury.

REFERENCES:

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Weight Loss

Malnutrition is a deficiency, excess, or imbalance in an individual's intake of energy and/or nutrients¹. This term covers two categories: undernutrition and being overweight. Individuals with dementia are at high risk for unintentional body weight loss, a form of malnutrition. The risk of malnutrition for individuals with dementia living in the community is between 15% and 42%^{2,3}. For these individuals, weight loss can have severe consequences including a rapid decline in cognitive ability, delayed healing from infections, muscle loss, loss of independence, and increased mortality. Unintentional weight loss is also correlated with increased burden for caregivers. In individuals with dementia, those most likely to be malnourished are older, more cognitively impaired, more dependent in activities of daily living (ADLs), and have more behavioral symptoms associated with dementia such as agitation or hallucinations².

Weight loss is a sign that dementia is advancing to later stages and is an expected finding in individuals with dementia in the moderate to severe stages. However, early recognition of factors contributing to feeding problems can delay malnutrition and increase quality of life.

Assessment

The cause of malnutrition is often multi-factorial. The risks for malnutrition can be categorized as medical, psychological, or social⁴. Mealtime routines and feeding should be assessed via observation of a meal and caregiver interview.

Medical Risk Factors	Social Risk Factors	Psychological Risk Factors
Poor appetite	Lack of knowledge about food, cooking	Confusion
Dysphagia	Isolation/loneliness	Depression
Poor dentition	Poverty	Bereavement
Loss of taste and smell	Inability to shop or prepare food	Anxiety or agitation
Chronic dyspnea	Caregiver knowledge and skill with food preparation	
Gastrointestinal disorders such as malabsorption or reflux		
Endocrine disorders such as diabetes or thyroid problems		
Physical disability		
Drug side effects or interactions		
Cognitive changes including dementia		
Visuospatial perception changes		

Treatment

The treatment approach for weight loss is dependent on the cause(s) of the weight loss. A combination of medical/physiological, psychological, and social interventions may be appropriate depending on the person with dementia.

Interventions for Medical and Physiological Factors

- Discuss nutrition supplements with the primary care provider
- Discuss laboratory testing with the primary care provider, such as a CBC, Vitamin B12, folate levels
- Consider medications. For example, acetylcholinesterase inhibitors prescribed for Alzheimer's disease and other dementias (donepezil, rivastigmine, and galantamine) can cause nausea, vomiting, weight loss and diarrhea
- Talk to family about missing dentures or dentures in need of repair

Interventions for Psychosocial Factors

- Refer to social work for programs to address food insecurity program such as Meals on Wheels
- Encourage caregivers to eat with the individual to increase socialization
- If you suspect depression, discuss with the primary care provider and caregivers
- Explore opportunities for fun, pleasure, and socialization around meals, such as a regularly weekly lunch visit from a family member, or an outing to a restaurant at off-peak times of day if the person is able
- Explore feasibility of replacing three meals per day with more-frequent small meals, to increase the frequency of opportunities to eat
- Ask the caregiver about their skills for meal prep, and talk with them about any barriers they encounter in making meals available

Occupational Therapy Interventions

- OT assesses family meal time routines, self-feeding abilities of person with dementia, and may recommend devices and strategies to help with self-feeding skills
- Develop a multisensory cueing schedule with the caregiver to compensate for attention and memory deficits
- Build up seating support to compensate for individual's strength and balance
- Try place-setting items that compensate for visuospatial, motor, and sensation changes
- Advise caregivers to serve at least one food with favorite flavors and textures (as appropriate per SLP recommendations) at each meal

Speech Therapy Interventions

Speech therapy can assess swallowing and may suggest:

- Texture and consistency of food and liquids to match the person's swallowing ability
- Training caregivers to coach the individual in swallowing techniques
- Signs for caregivers to watch for indicating pain or difficulty swallowing

Percutaneous endoscopic gastrostomy (PEG) tubes

Many times, despite best efforts, weight loss doesn't resolve. The American Geriatric Society (AGS) advises against the use of PEG tubes in individuals with advanced dementia⁵. Research studies show that PEG tubes do not increase survival or quality of life, nor do they reduce incidence of aspiration pneumonia. The AGS states that PEG tubes are associated with adverse outcomes, such as increased agitation, development of new pressure injuries, greater use of chemical and physical restraints, and increased healthcare encounters to treat tube-related complications⁵. There are legal and ethical implications associated with whether to give someone with advanced dementia artificial nutrition. This is usually a difficult topic for families. The expressed wishes of the individual with dementia should be taken into account, if known. Consider a referral to palliative care or hospice if a family is considering placement of PEG tube. Palliative and hospice care providers are skilled at bring teams and families together to discuss complex decisions for individuals with dementia.

Care Plan Goals

1. Caregiver will name two ways to prevent weight loss.
2. Caregiver will describe two ways weight loss can be managed.

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Swallowing Problems

Information for Home Health Clinicians

Swallowing Problems

Dysphagia, or difficulty with swallowing, is a common consequence of dementia. In the moderate to severe stages, between 84% and 93% of people with dementia experience swallowing problems¹. Swallowing problems can lead to social and functional decline, weight loss, malnutrition, aspiration pneumonia, and death². A recent systematic review that explored the effectiveness of interventions to support the intake of food and fluids in people living with dementia revealed no compelling evidence to support or refute any single intervention³. There were some positive, if not proven to be clearly effective, strategies including family style meals, eating with caregivers, individual mealtime assistance, and a dysphagia diet³. As each person with dementia is an individual, with varied presentations and symptoms, it is reasonable to assume that any interventions for swallowing problems will need to be tailored to the person.

Normal swallowing requires an intact motor and sensory nervous system. As dementia progresses, each of the four stages of normal swallowing may become impaired. The chart below shows typical impairments due to dementia at each stage.

Stage of Swallowing	Potential Deficits in a Person Living with Dementia
Pre-oral	<ul style="list-style-type: none"> • Forgetting when last ate • Difficulty recognizing food and utensils • Difficulty performing actions like lifting spoon to mouth • Socially inappropriate mealtime behavior such as eating too quickly or slowly • Changes in poor posture or inability to sit due to physical weakness⁴
Oral	<ul style="list-style-type: none"> • Inability to move food from the front of the mouth to the back • Forgetting how to chew • Spitting lumps of food out of the mouth • Unable to open the mouth or inconsistently opens the mouth⁴
Pharyngeal	<ul style="list-style-type: none"> • Coughing • Choking • Absent swallow reflex • Aspiration
Esophageal	<ul style="list-style-type: none"> • Possibly impaired due to autonomic dysfunction⁵

Swallowing problems in the early stages may be subtle, but by the severe stage they are nearly universal. In early stage dementia, the person may have a change in food preferences, eat noticeably slower, or have trouble with utensils. The person may lose weight due to forgetting to shop for food, eat, or drink. Dehydration can be a problem even in the early stage⁴. In the moderate stage of dementia, the person may begin to cough with food or fluids (a sign of possible aspiration), forget how to chew, have difficulty concentrating at mealtimes, or not finish food on their plate⁴. In the severe stage, individuals with dementia are at high risk for dehydration, malnutrition, and aspiration resulting in pneumonia, and may lose the ability to manage his or her own secretions⁴. For any of these issues at any stage of dementia, it is appropriate to consult speech therapy. Speech therapy is vital to minimizing the risk of serious adverse outcomes through swallow assessment and targeted interventions to improve oral nutrition and hydration. It is important to note that in the later stages of the disease, it is not possible to reduce the risk of aspiration to zero⁶.

Assessment

Although a comprehensive swallowing assessment is the domain of speech therapists, any clinician can watch for swallowing difficulties to educate caregivers, request modified orders for medications, and refer for speech therapy if not involved. The assessment should include:

- Detailed history of eating or swallowing problems, including a history of coughing with eating or drinking. The history should look for impairments across all phases of swallowing. Input from a caregiver or aide who has observed the person eating is essential
- Assessment of any oral problems such as poor fitting dentures or mouth sores
- Review of medications that can contribute to malnutrition, weight loss, and dry mouth, including those used to treat dementia
- Recent changes in function, memory, or behavior
- Feeding trial:
 - Watch the person eat and drink to observe impairments in all phases of swallowing²
 - Check for pocketing of food in the cheek
 - Observe seating and positioning during meals, and whether it compromises a safe oropharyngeal orientation
 - Listen for hoarse or gargling vocal quality after eating and drinking, which can occur when food or liquid goes into the airway during swallowing

A swallowing assessment may be needed intermittently as the person with dementia progresses into later stages. For any signs or symptoms of dysphagia, a speech therapy swallowing evaluation is indicated, as well as notifying the primary care provider to perform a complete assessment. This is essential to minimize the risk of pneumonia. The speech therapist helps modify the diet and teach techniques to reduce aspiration risk. An occupational therapist can support swallowing by assessing the meal time routine, positioning and set-up, and the individual's self-feeding abilities. They may design intervention strategies such as pacing the presentation of foods (e.g., one food at a time), using dishes that contrast in color with the food served, and adaptations for self-feeding. Good oral care before and after meals can also help avoid complications of dysphagia such as aspiration pneumonia.

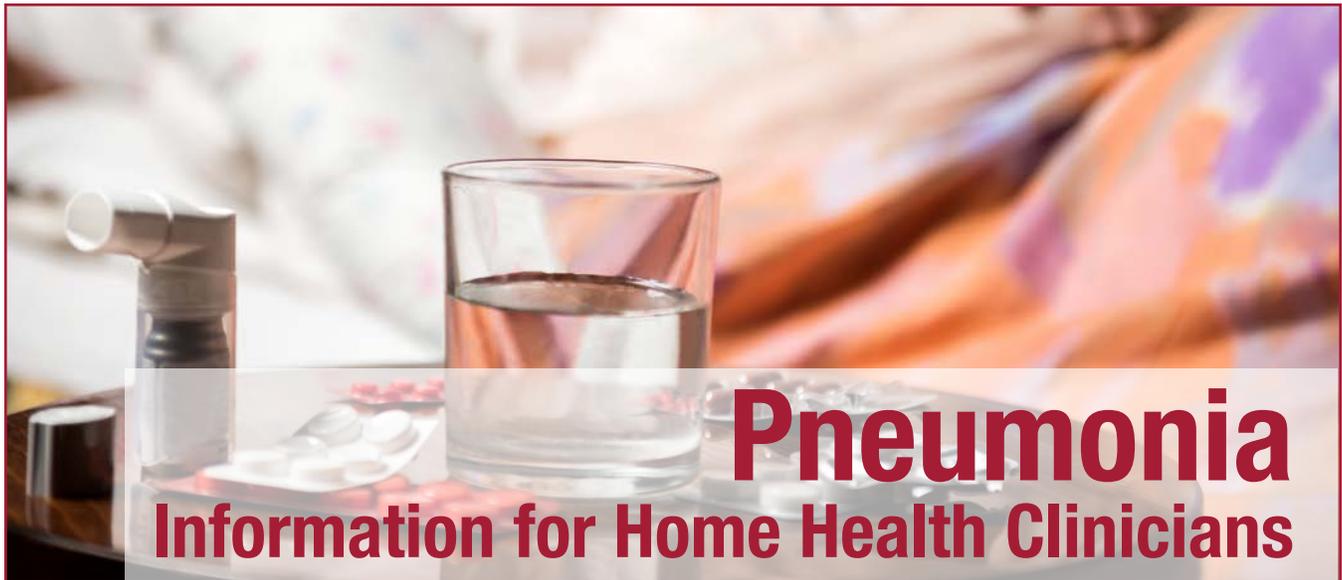
Home health clinicians are instrumental in educating caregivers about dysphagia, risks of aspiration, and appropriate management strategies for eating and drinking problems in people with dementia. The Edinberg Feeding Evaluation in Dementia Scale (EdFED) is an 11-item tool that can be administered in less than 5 minutes and used to determine the level of assistance needed by a person living with dementia at mealtime⁷. The tool is appropriate for use in individuals with moderate to severe dementia who have been losing weight, or showing problems with eating or drinking⁷.

Care Plan Goals

1. Caregiver will identify one way to prevent swallowing problems in a person with dementia.
2. Caregiver will name one sign that a person is having difficulty swallowing.
3. Caregiver will identify one way to manage swallowing problems.
4. Caregiver will identify what to do if it looks like a person is aspirating with eating or drinking.

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1. Boccardi, V., Ruggiero, C., Patrini, A., & Marano, L. (2016). Diagnostic assessment and management of dysphagia in patient with Alzheimer's disease. *Journal of Alzheimer's Disease, 50*, 947-955.
2. Jiang, J.-L., Fu, S.-U., Wang, W.-H., & Ma, Y.-C. (2016). Validity and reliability of swallowing screening tools used by nurses for dysphagia: A systematic review. *Tzu Chi Medical Journal, 2016*, 41-48.
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Pneumonia

Pneumonia is the 7th leading cause of death in the US, responsible for 50,000 deaths and 1 million hospitalizations¹. Risk factors for pneumonia include old age, smoking, and chronic disease, including dementia. Individuals with dementia are twice as likely to die from pneumonia as those without dementia². In a recent study of nursing home residents with advanced dementia and pneumonia, the 10-day mortality rate was 48% and the 6-month mortality rate was 74%, even though 77% of the sample were treated with antibiotics³. For individuals with dementia, the risk factors for developing pneumonia include:

- Use of antipsychotics, benzodiazepines or anticholinergic medications – especially in the first 30 days of use^{4,5}
- Use of a Proton Pump Inhibitor (PPI)
- Smoking
- Male gender
- Cerebrovascular disease
- Chronic pulmonary disease
- Congestive heart failure (CHF)
- Diabetes⁶

Prevention

All older adults should be vaccinated against influenza. In addition, older adults should receive two immunizations for pneumonia, the pneumococcal conjugate vaccine (Prevnar 13) and a pneumococcal polysaccharide vaccine (Pneumovax23). *Streptococcus pneumoniae* is the most common cause of pneumonia and therefore vaccination on the appropriate schedule is key to prevention. The person with dementia should be assessed for proper positioning during meals and the ability to safely swallow to avoid aspiration. Safe physical activity, including upright positioning when sitting, is beneficial for respiratory health and functional capacity, a risk factor for pneumonia.⁷ People with dementia who continue to smoke should be encouraged to quit. Others living in the home who smoke, should be instructed to do so outside.

Assessment

The typical signs and symptoms of pneumonia may be absent or difficult to assess in older adults, especially those with dementia. The common presentation of pneumonia includes fever, chills, cough productive of purulent sputum, fatigue, and shortness of breath. Cough and shortness of breath are common complaints among older adults, so it is important to know if a cough is new or worse than usual. In older adults, crackles on the exam are absent about 50% of the time when pneumonia is present. Older adults are less likely to have a fever. In individuals with severe dementia, the cough may also be absent. Consider pneumonia for any patient

with new or worsening dyspnea and tachypnea. Older adults can show other atypical signs of pneumonia such as chest pain, nausea, vomiting, abdominal pain, diarrhea, or lack of appetite. Even without the classic signs and symptoms (fever, cough, dyspnea), suspect infection in an older adult with:

- A sudden change in functional status
- A sudden change in mental status
- Signs of dehydration
- An elevated WBC

Types of Pneumonia

Community acquired pneumonia (CAP) – Increased morbidity and mortality among older adults

Healthcare associated pneumonia (HCAP) – Incidence is 3 X higher among older adults

Viral pneumonia – Associated with a history of influenza A

Aspiration pneumonia – Higher incidence among individuals with dementia

Treatment

The decision of whether and in what setting to treat an individual with dementia who develops pneumonia is complex. Pneumonia is the leading cause of death from infection among older adults and a common complication at end of life for individuals with dementia. In the case of severe dementia, family members may choose to forego antibiotics and focus on comfort if the individual develops pneumonia. This decision should be made in consultation with the healthcare team and with the support of hospice care if possible.

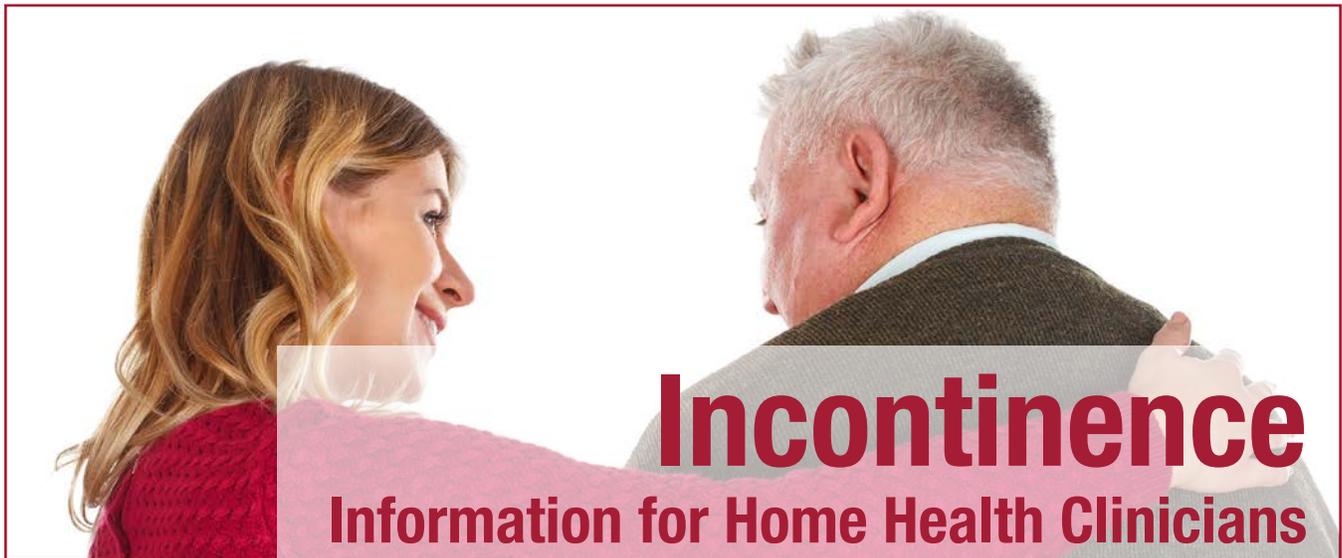
The setting for treatment will depend on the severity of the illness and the wishes of the person with dementia and their family. If the wishes are to treat the illness, consider hospital admission for patients who present with poor oral intake, rapid functional decline, respiratory rate > 30, systolic blood pressure < 90 mm/Hg, or diastolic BP < 60 mm/Hg, decline in renal function, hypothermia, or bilateral or multi-lobe infiltrates.

Care Plan Goals

1. Caregiver will name two ways to prevent pneumonia.
2. Caregiver will name two symptoms of pneumonia in an individual with dementia.
3. Caregiver will describe how to avoid a hospitalization for pneumonia.

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Incontinence

Urinary incontinence is the “involuntary loss of urine which is objectively demonstrable and a social or hygienic problem”¹. Incontinence is not a disease in itself, but a symptom that corresponds to various social and pathophysiological factors. It is not a normal part of aging. Incontinence is often treatable, not just “containable.” A recent systematic review concluded there are currently no definitive prevalence data for urinary incontinence among persons with dementia². Estimates of the incidence of incontinence in people with dementia range from 53 to 90 percent³.

Incontinence has been shown to be a contributing factor in the decision to admit a person with dementia to long-term care². In order to maintain continence, a person needs a functioning lower urinary tract, adequate cognition, physical mobility, motivation, and a supportive environment⁴. Many of these necessities for continence may be a challenge for a person with dementia. Aside from long-term care placement, the consequences of incontinence include depression, anxiety, falls, fractures, sleep disturbance due to nocturia, pressure injury, and urinary tract infections⁴.

Assessment

It is important to thoroughly assess for incontinence as soon as possible when it arises or worsens. A person with dementia or a family caregiver may delay seeking treatment for incontinence due to shame or embarrassment⁵. Caregivers may be reluctant to discuss incontinence if they do not perceive it as a problem that can be treated or managed, but feel it must be accepted as part of the disease or aging. The purpose of a thorough assessment is to determine the type of incontinence and identify factors contributing to it.

Types of incontinence:

Acute Incontinence – Sudden onset, associated with a medical or surgical condition; Medication or infection, such as a urinary tract infection, should be suspected in cases of acute onset incontinence

Chronic Incontinence – Continues and worsens over time; Major causes are stress, urge, overflow, and functional incontinence

Stress Incontinence – Loss of urine as the result of increased intra-abdominal pressure, such as with coughing, laughing, or sneezing

Overflow Incontinence – When a chronically full bladder increases bladder pressure, overcoming urethral resistance

Functional Incontinence – Loss of urine due to inability or unwillingness to toilet, resulting from physical, mental, psychological, or environmental factors

Mixed Incontinence – A combination of two or more types of incontinence

A person with dementia could have any type of incontinence. However, dementia is associated with urge incontinence and functional incontinence due to decreased motivation and initiative to toilet, social disinhibition, decreased executive function, immobility or gait disturbance, and severe autonomic failure such as with Lewy body dementia⁴.

Important elements of the assessment include:
Onset
Frequency or volume of accidents
Circumstances around the urine loss
Bladder habits
Daily fluid intake
Previous evaluation
Current management techniques (caregiver's current strategies) <ul style="list-style-type: none"> • Incontinence products • Restriction of fluids • Scheduled toileting or prompted voiding • Equipment used for toileting
Any other urinary symptoms
Bowel habits
New medications or medication changes
Functional assessment (whether the person can physically get to the bathroom and understand how to use it) <ul style="list-style-type: none"> • Mobility • Environmental set-up and barriers • Level and type of cueing the person with dementia benefits from to participate in self-care

Drugs that cause or contribute to incontinence are⁴:
Alcohol
Alpha adrenergic agonists, such as midodrine or pseudoephedrine
Alpha blockers, such as doxazosin or tamsulosin
ACE inhibitors
Caffeine
Cholinesterase inhibitors, such as donepezil or rivastigmine
Diuretics
Anticholinergic drugs, such as diphenhydramine
Opioids
Sedatives and hypnotics

Management

The management of urinary incontinence is dependent on the cause or contributing factors. Utilize the multidisciplinary team to manage incontinence. The primary care provider should assess the person with dementia for any new onset or worsening symptoms of incontinence. Physical and occupational therapy will optimize the person's abilities while adapting to changes related to dementia by coaching the caregiver on cueing strategies, environmental set-up, equipment selection and installations, routines, safe transfer, and mobility assistance. Interventions should be tailored to the individual and his or her caregiver and environment.

Although some medications to manage incontinence pose a risk to individuals living with dementia due to their anticholinergic properties, medications may be used and can be appropriate. It is important to look at the overall anticholinergic load of all medications taken by the individual, and weigh potential benefits for the patient and caregiver against potential risks. Although managing urge incontinence in an individual with dementia presents major challenges, the benefits of any improvement in continence should not be underestimated⁴.

Care Plan Goals

1. Caregiver will name two ways to prevent urinary incontinence.
2. Caregiver will state two characteristics of urinary incontinence that should trigger a call to the health care provider.
3. Caregiver will describe two ways to manage urinary incontinence.

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Constipation

Constipation is a gastrointestinal symptom, rather than a disease. There are generally two types of constipation, transit abnormalities and defecation difficulties. The former results in decreased frequency of bowel movements. It can be difficult to define constipation, as the frequency of bowel movements and characteristics of “normal” vary among individuals and across cultures¹. Chronic constipation is defined by the Rome III criteria², which requires two or more of the following symptoms present for at least 12 weeks in the previous 6 months:

- Straining at defecation at least 25% of the time
- Emptying stools that are lump/hard at least 25% of the time
- Experiencing a sensation of incomplete evacuation at least 25% of the time
- Having three or fewer bowel movements a week²

Chronic constipation affects 30% of adults over age 65, and up to 50% of adults over 65 in nursing home or hospital settings³. Risk factors for constipation include underlying medical conditions, medication side effects, lack of appropriate toileting facilities or assistance with toileting, reduced mobility, and inadequate oral intake of food and fluids¹.

Assessment

Like many other conditions, it can be difficult to identify constipation in a person living with dementia due to communication impairment, memory problems, and the atypical presentation of common health problems. The consequences of untreated constipation include hemorrhoids, anal fissures, fecal impaction, rectal prolapse, and bowel obstruction. Constipation can lead to hospitalization due to fecal impaction. Constipation can cause pain, distress, and discomfort. This can result in behavioral or psychological symptoms of dementia such as agitation, increased vocalizations, or wandering. Due to the variety of “normal” bowel patterns among individuals, the first step in assessment is establishing the baseline. Ask caregivers to record bowel movements, even if constipation is not currently a problem. The bowel record will serve as a useful baseline to rule out whether constipation is a problem in the future if there is a change in behavior, functional status, mood, or even a fever.

When constipation is a concern, assess the person and environment, medical causes, and medications that could cause or contribute to constipation.

Person and environment:

- What is the baseline pattern of bowel movements?
- Can the client sit on a toilet in the appropriate position with or without support?
- Does the person know where the bathroom is located?
- Is the environment suitable? (toilet close by, bathroom warm, stocked with toilet paper, private, equipped with grab bars)
- Can the client safely move to the bathroom and back?

Medical causes:

- Irritable bowel syndrome
- Cancer
- Diverticular disease
- Hypothyroidism
- Pelvic floor dyssynergia
- Structural lesions
- Lack of mobility
- Dehydration
- Stimulant/laxative abuse
- Bowel obstruction
- Hypercalcemia
- Physical immobility
- Lack of dietary fiber

Medications that cause or contribute to constipation:

- 5-HT₃ antagonists (ondansetron)
- Calcium or aluminum-containing antacids
- Calcium channel blockers (amlodipine, verapamil)
- Drugs with anticholinergic effects (antidepressants, antipsychotics, antihistamines, antispasmodics)
- Ferrous sulfate
- Opioid analgesics
- Calcium supplements
- Phenothiazines¹

Management

Steps in managing chronic constipation:

1. Identify and treat the underlying cause.
2. Increase fluid intake to more than 1500 mL /day and dietary fiber to 6–25 g/day. Increase physical activity, if possible.
3. Discuss adding the following medications with the Primary Care Provider, in this order:
 - Bulking agent
 - Osmotic agent
 - Stimulant laxative
 - Colonic secretagogue 2–3 times/week
 - “Power Pudding”

If a fecal impaction is present, this should be managed first by manual disimpaction, followed by several warm-water enemas to evacuate the rectum. After local disimpaction, a polyethylene glycol preparation should be used to cleanse the colon⁴.

Mobility and positioning

As a client's dementia advances, movement becomes more difficult. This can be due to structural changes in the motor, visual, and sensory cortices, confusion and agitation, visuospatial processing changes, and fatigue. Motility is slowed as a client's activity level decreases. Working with the caregiver to create routine that includes opportunities to move several times per hour during wakeful hours, and is based on their needs and abilities, can help decrease constipation.

Medications to Treat Constipation		
Medication Class	Onset of Action	Examples
Bulk laxatives	12- 72 hours	Methylcellulose (Citrucel), Psyllim (Metamucil), Polycarbophil (Fibercon)
Osmotic laxatives	24-96 hours	Polyethelene glycol (Miralax), Lactulose, Sorbitol 70%
Stimulant laxatives	15 minutes to 10 hours	Bisacodyl tablet (Dulcolax), bisacodyl suppository (Dulcolax), Senna (Senokot)
Colonic secretagogues	48-96 hours	Lubiprostone (Amitiza), Linaclotide (Linzess)

Care Plan Goals

1. Caregiver will name two ways to prevent constipation.
2. Caregiver will name two signs of constipation in an individual with dementia.
3. Caregiver will describe two ways to manage constipation.

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Pain

Information for Home Health Clinicians

Pain

There are many challenges to preventing, assessing, and treating pain in older adults living with dementia. In the general older adult population, the prevalence of chronic pain has been estimated to vary between 20% and 50%¹. In a recent study, the prevalence of chronic pain was double in individuals with dementia compared to those without dementia¹. Health care providers are taught to assess pain through self-report, but individuals living with dementia may not be able to verbally communicate pain. Pain can also be an underlying cause of behavioral and psychological symptoms of dementia (BPSD), such as anxiety, agitation, moaning, and crying. Between 80-85% of individuals with dementia experience BPSD. The pain assessment is especially difficult with the presence of BPSD. An individual with dementia who has pain exhibiting BPSD may receive antipsychotic medications rather than pain treatments, relieving neither the pain nor the BPSD.

Pain is often under-detected and under-treated in individuals living with dementia¹. The potential consequences of unrelieved pain are numerous and significant. BPSD can decrease quality of life, and increase the cost of care, caregiver burden, and depression². Aside from BPSD, persistent pain can also lead to depression, anxiety, increased hospitalizations, premature death, loss of functional ability, decreased socialization, and impaired sleep^{3,4}.

Assessment

It is vitally important to accurately assess pain in order to adequately treat it. Due to the loss of communication ability in many older adults with moderate to severe dementia, an accurate assessment can be challenging. A thorough pain assessment should include the individual's verbalization or self-report of pain whenever possible, as well as a thorough examination. Pain assessment instruments have been developed to assess pain in patients with dementia, such as:

- Assessment of Pain in Advanced Dementia Scale (PAINAD)⁵
- Visual Analog Scale (VAS)
- Faces Pain Scale (FPS)⁶

Caregiver report is another important aspect of the pain assessment, especially when the person can no longer give a self-report. The caregiver may know signs of pain specific to the individual, or know aspects of the patient's medical history that can contribute to an investigation of sources of pain.

One way to assess pain is through observation of behavior. This is when a caregiver history is vitally important. The American Geriatric Society (AGS) Panel on Persistent Pain in Older Persons provided a list of common pain behaviors in older adults with dementia⁷.

The physical exam may help to identify the cause of pain or expressions of pain such as BPSD. A study conducted in nursing homes found that common sources of pain among individuals with dementia include:

- Musculoskeletal
- Gastrointestinal conditions
- Cardiac conditions
- Urinary tract infections
- Pressure injuries
- Orofacial conditions⁶

Musculoskeletal pain can be assessed through palpation and gentle range of motion. Visceral pain from internal organs and neuropathic pain can be much more challenging to assess. Up to 35% of individuals who have had a stroke suffer from post-stroke neuropathic pain. This is important to keep in mind when caring for individuals with vascular dementia.

Treatment

Individuals with dementia receive less pain medication than individuals without dementia. They are also less likely to receive opioids, and when they do the dose is usually 30% of the dose prescribed to individuals without cognitive impairment⁸. There is a lack

of research studies looking at the efficacy of pain medications in individuals with dementia. Most treatment strategies are experience-based and are likely to differ from provider to provider. We do know that pain is under-recognized and under-treated in this population, so for any change in behavior or function, uncontrolled pain should be high on the list of possible causes. Advocate for the patient to receive appropriate pharmacologic and non-pharmacologic pain treatment. The most appropriate first-line pharmacologic treatment for pain or suspected pain is acetaminophen, up to 3,000 grams daily, given on a scheduled basis⁹. There is good evidence to suggest that pain management can reduce BPSD⁸.

AGS Signs of Pain	
Facial expressions	<ul style="list-style-type: none"> • Slight frown, sad, frightened face • Grimacing, wrinkled forehead • Closed or tightened eyes • Any distorted expression • Rapid blinking
Verbalizations, vocalizations	<ul style="list-style-type: none"> • Sighing, moaning, groaning • Grunting, chanting, calling out • Noisy breathing • Asking for help • Verbally abusive
Body movements	<ul style="list-style-type: none"> • Rigid, tense body posture, guarding • Fidgeting • Increased pacing, rocking • Restricted movement • Gait or mobility changes
Changes in interpersonal interactions	<ul style="list-style-type: none"> • Aggressive, combative resisting care • Decreased social interactions • Socially inappropriate, disruptive • Withdrawn
Changes in activity patterns or routines	<ul style="list-style-type: none"> • Refusing food, appetite change • Increase in rest periods • Sleep, rest pattern changes • Sudden cessation of common routines • Increase wandering
Mental status changes	<ul style="list-style-type: none"> • Crying or tears • Increased confusion • Irritability or distress

- American Geriatric Society, 2002

Care Plan Goals

1. Caregiver will name two ways to prevent pain.
2. Caregiver will name two signs of uncontrolled pain in an individual with dementia.
3. Caregiver will describe two methods to treat pain in an individual with dementia.

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Assessment

Older adults with infections have significantly higher morbidity and mortality than younger adults¹. Prompt evaluation and management of infections can prevent complications, hospitalizations, and death due to infectious disease. Early identification of infection is difficult because older adults often do not show classic signs of illness. This is especially true for older adults with a cognitive impairment, such as dementia¹. In a recent study of older adults treated for infection at an emergency department, dementia was an independent risk factor for the likelihood of an atypical presentation.

Fever, a sign almost universally recognized as a sign of infection, is absent in frail older adults with a serious infection up to 50% of the time³. The baseline temperature of older adults is typically lower than the younger adult population. Consider the following as evidence of infection in frail older adults:

- A temperature > 2° F above baseline
- Oral temperature > 99° F or rectal temperature > 99.5° F on repeated measures
- Single oral temperature > 100° F⁴

Lack of fever is not the only atypical sign of infection among older adults. Older adults with meningitis may not have a stiff neck, or may not be able to differentiate a stiff neck from chronic pain due to osteoarthritis. There may be no abdominal pain despite an acute intra-abdominal infection¹. Pneumonia may be present without cough⁵. In one study, just 31% of older adults with pneumonia had the typical signs and symptoms – cough, dyspnea, and fever⁵. When older adults do present with signs and symptoms of an infection, the way they present often does not match the severity of the illness¹.

It's very important to know a client's baseline in order to identify signs of a potential infection. Suspect infection for the following¹:

- Acute change in mental status
- Decline in function
- Anorexia
- Falls
- Urinary or fecal incontinence
- Tachypnea

Notify the primary care provider for any of these changes. People with moderate to severe dementia usually cannot communicate symptoms. Providers need a lower threshold for pursuing objective evidence of infection, such as laboratory and imaging tests³.

Management

When the goal is to treat the infection, early identification and treatment is key to avoiding emergency room visits and hospitalizations. The wishes of the client should be the first consideration for management of a suspected or confirmed infection in a person living with moderate to severe dementia. There is evidence to suggest that antibiotics offer little benefit to individuals with advanced dementia for urinary tract infections and pneumonia^{6,7}. If the goal of care is for comfort, the provider may decide with the family to forego both evaluation and treatment for an infection. See the Palliative and Hospice Module for further information.

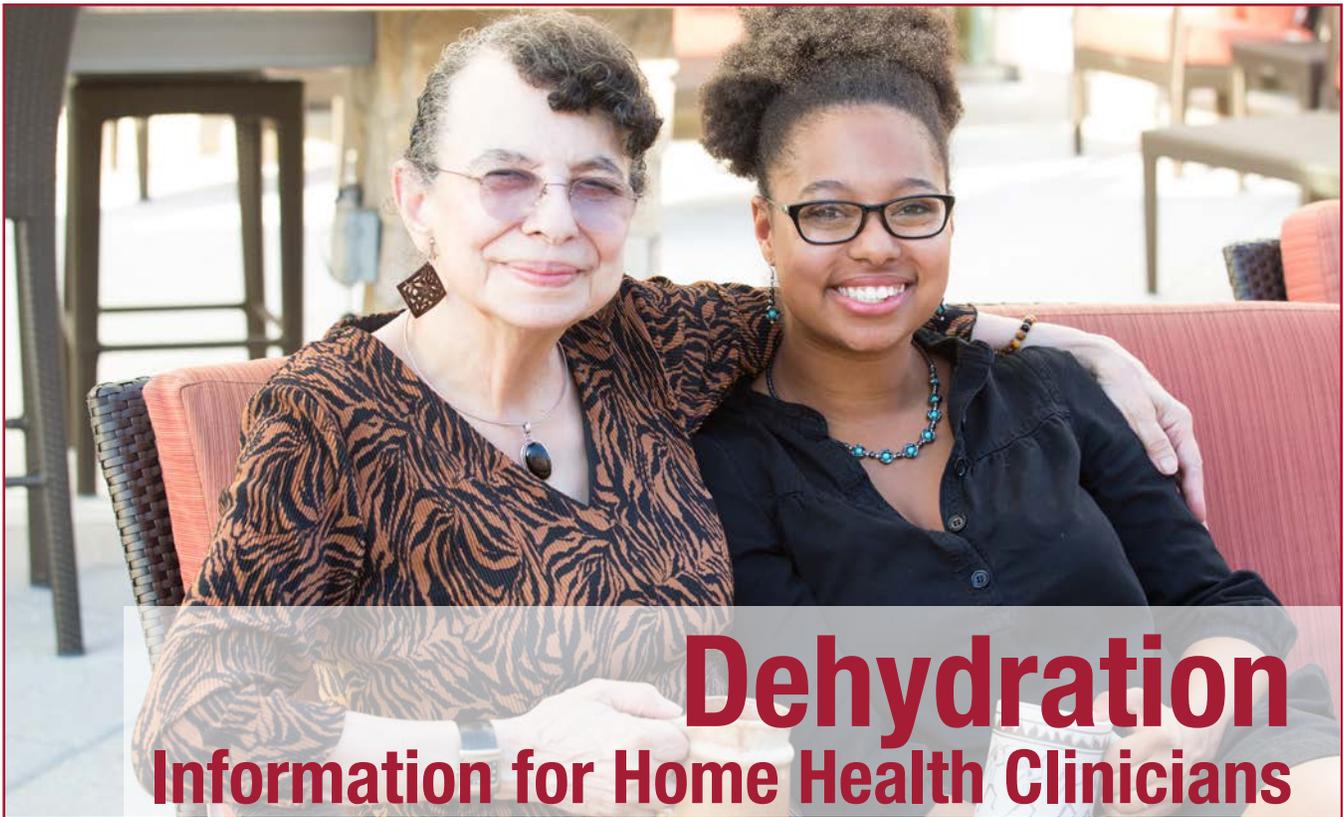
Older adults are more susceptible to nosocomial infections encountered during acute care visits¹. Older adults with dementia often experience irreversible cognitive and functional decline during a hospital stay. Ideally, the infection will be treated at home with oral antibiotics.

Care Plan Goals

1. Caregiver will be able to name one method to prevent infection.
2. Caregiver will be able to name one sign or symptom of infection.
3. Caregiver will be able to describe what to do if he/she suspects infection.

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Dehydration Information for Home Health Clinicians

Dehydration

The annual cost of preventable hospitalizations for older adults with a primary diagnosis of dehydration in the U.S. is between \$1.1 to \$1.4 billion¹. As a result of the physiological changes of aging, older adults are more susceptible to dehydration due to decreased total body water, decreased sense of thirst, and decreased kidney function^{2,3}. Due to impaired homeostatic mechanisms in aging, small decreases in fluid intake can cause dehydration very quickly. Other factors that contribute to dehydration in older adults include a fear of incontinence, medications, lack of air conditioning, dysphagia, and frailty⁴. Persons with dementia are especially susceptible to dehydration due to mobility problems, loss of executive function, and inability to communicate his or her needs. Dehydration can lead to delirium, falls, thromboembolic complications, kidney stones, renal failure, pressure injuries, infection, drug toxicity, and death^{5,6}. In one study, mortality from dehydration exceeded 50% in older adults⁷. **Preventing dehydration or treating it early in the home can eliminate dehydration-related emergency room visits and hospitalization.**

There are three main categories of dehydration:

Isotonic dehydration – loss of sodium and water. A typical cause of this form is gastrointestinal illness.

Hypertonic dehydration – water loss exceeds sodium loss. This is the most common form of dehydration and can occur from fever or limited fluid intake.

Hypotonic dehydration – sodium loss is higher than water loss. This can be caused by diuretic use.

Assessment

Assessing dehydration in older adults requires a multi-component, individualized approach. A recent systematic review found insufficient evidence to recommend a specific clinical assessment to identify older adults at risk of poor oral intake⁸. Additionally, there is no single clinical test, sign, or symptom to indicate water-loss dehydration in older adults⁶. The typical signs of dehydration include absent axillary moisture, orthostasis, hypotension, and low urine output⁹. However, these signs are not reliable in older adults⁶. For example, older adults' ability to concentrate urine is impaired due to physiological

changes of aging. Therefore, concentrated urine or a reduced urine output is not an early sign of dehydration in older adults⁹. The best classic indicators of dehydration among older adults may be dry oral mucosa and abnormal skin recoil time at the forearm or subclavicular region⁵. However, these tests should not be used as a stand-alone indicator of water-loss or hypertonic dehydration. Other unreliable signs and symptoms include fluid intake, urine specific gravity, urine color, heart rate, dry mouth, and feeling thirsty⁶.

It is important to know a client's baseline status in terms of intake, mental status, mobility, and function. Taking this knowledge into account in addition to caregiver history and physical signs of dehydration may be key to identifying those at risk of experiencing dehydration. The signs of dehydration may be subtle, such as decreased mobility or fatigue.

There are common medications that contribute to dehydration. Critically examine the medication list. Consult with the primary care provider to cut back on one or more of these medications if you suspect dehydration:

- Diuretics
- Antidepressants
- Antipsychotics
- Anticonvulsants
- Medicine with anticholinergic properties
- ACE and ARB inhibitors
- Benzodiazepines

Treatment

Treatment of dehydration should be tailored to the individual. Clinicians and family members should take into consideration the overall goals of care. If the individual has advanced dementia and the inability to safely swallow is contributing to dehydration, this should prompt a discussion about end of life planning and hospice care.

A sedentary older adult should drink a minimum of 1500 mL of liquid (approximately eight drinks) per day, as a general rule⁴. However, there is a great deal of variability in how much an older adult might drink, making baseline history important. Consider consulting speech therapy and occupational therapy when there are concerns about the person's ability to swallow.

Oral rehydration is the least invasive method to prevent and treat dehydration. Caregivers are instrumental in preventing and treating dehydration by frequently offering drinks. Methods to encourage oral hydration include serving beverages at the appropriate temperature, offering flavored or favorite drinks, and serving drinks in brightly colored containers that do not blend into the surroundings¹⁰. Any fluids can be helpful, such as water, milk, juice, or broth. Tailor the fluids offered to the tastes of the individual. When a person with dementia refuse any fluids, it may be possible to stimulate drinking by first offering a mouth swab with a flavored drink to the lips, then offering the drink in a cup¹¹.

Subcutaneous rehydration therapy, also called hypodermoclysis, is a method of rehydration where a butterfly needle placed in the subcutaneous tissue is used to infuse 0.9% sodium chloride slowly over 8 to 24 hours at a rate of 1 mL per minute by gravity or infusion pump¹². Subcutaneous rehydration is an option for individuals with poor vascular access and may be better tolerated by or less painful for individuals with dementia. It is important to monitor for local edema. Subcutaneous rehydration is a safe and effective alternative to intravenous (IV) infusion and can be administered in the home setting¹². There is a risk for ligature. This method should not be used for a person with severe dehydration.

The most invasive form of rehydration therapy is an IV infusion. Intravenous fluids are more costly than subcutaneous fluids but are appropriate for severe dehydration or electrolyte disturbance. The primary care provider, nurse, and caregiver should be involved in a decision to provide IV fluids for dehydration in the home.

Care Plan Goals

1. Caregiver will name two ways to prevent dehydration.
2. Caregiver will name two signs or symptoms of dehydration.
3. Caregiver will describe two ways to manage dehydration.

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Behavior Changes

Information for Home Health Clinicians

Behavior Changes

Most people with dementia experience behavioral and psychological symptoms of dementia (BPSD), sometimes referred to as “challenging behaviors,” including depression, apathy, hallucinations, delusions, aggression, agitation, sleep disturbance, and wandering¹. These behaviors can have a significant adverse impact on caregivers and are strongly linked to early institutional placement, increased morbidity and mortality, and hospital admissions^{1,2}. If BPSD were not present earlier in the disease process, they often emerge and become a significant feature of moderate and severe stage dementia. Although cognition and function decline over time with dementia, BPSD tend to fluctuate episodically². Among individuals living with dementia, those with untreated BPSD have a faster disease progression². The symptoms are primarily caused by progressive brain damage, but there are a myriad of other factors that can contribute, such as:

- Comorbid medical conditions (constipation, dehydration, sleep disturbance)
- Medication side effects (benzodiazepines, opiates, anticholinergic medications)
- Infections (UTI, pneumonia)
- Pain
- Unmet needs (boredom, loneliness, inactivity)
- Environmental changes or transitions (noise, temperature)
- Caregiver factors (stress, depression, communication techniques, cultural factors)
- Psychiatric conditions (major depression, anxiety, bipolar, schizophrenia)^{2,3}

Assessment

The approach to preventing, assessing, and managing BPSD needs to be individualized to the person with dementia and the caregiver. There are some evidence-based tools for documenting BPSD, such as the Cohen-Mansfield Agitation Inventory, Dementia Observation Scale, or Behavior Pattern Record. These tools describe the observable behaviors and patterns which may help determine the cause of the behaviors. There are three main approaches to assessing BPSD, they include the **ABC method**², the **Environmental Vulnerability/Reduced-Stress Threshold** approach⁴, and the **unmet needs** method². The ABC method involves looking at the Antecedent circumstances that may have contributed to the Behavior, as well as the Consequences that might be reinforcing the behavior⁵. For example, the person with dementia yells, “Hello? Hello?” (Behavior) as the caregiver is talking on the phone in an adjacent room. The caregiver begins to talk more loudly on the phone (Consequence), and the person with dementia begins to yell even more loudly. An Antecedent factor could be that the person with dementia has cognitively declined so he can no longer process that the caregiver is not talking to him. The environmental vulnerability perspective looks for poor fit between a person’s environment and their ability to adaptively respond as dementia progresses.

The unmet needs method is a way of understanding BPSD as an expression of need from an individual who can no longer adequately communicate what is troubling him or her⁴. The unmet need may be physical or psychological. All three methods require a thorough investigation and understanding of the factors that can result in BPSD.

Management

Non-pharmacological methods for managing BPSD are considered first line, in the absence of an emergency or immediate safety concern². This can include communication that validates the experience of the person with dementia, caregiver coaching to reduce hazards and environmental stimuli related to individual's challenging behaviors, and skills for attuning to unmet needs⁶⁻⁷. One such approach is called the DICE Approach. There are 4 steps in the DICE Approach. The DICE Approach requires input from the caregiver and the healthcare provider.

DICE APPROACH™

Describe – The caregiver describes the behavior and its context

Investigate – The provider thoroughly investigates possible causes of the problem behavior. This includes looking for medical causes as well as non-medical (unmet needs, environment, caregiver factors, psychiatric conditions)

Create – Together, the caregiver and provider collaborate to create and implement a treatment plan

Evaluation – The caregiver and provider evaluate the treatment plan to see if it's working. DICE steps are repeated if behavior persists.

The DICE Approach requires a detailed description of the behavior and the context, including when and where it happens, who was present, how often and how distressing it is to others. The provider and caregiver investigate by taking into consideration the relationship between all possible factors including the health of the person with dementia, the role of the caregiver, and cultural and environmental factors. The provider and caregiver create a plan that addresses the etiology of the behavior. The plan would include treating any medical cause and using generalized or targeted behavioral strategies, such as restructuring or simplifying tasks or enhancing communication between caregiver and the person with dementia. Finally, the provider and caregiver evaluate whether the intervention took place, was fully implemented, was safe, and if the result was the intended consequence⁸. A new plan is initiated and evaluated if the behavior didn't resolve after implementing the first plan.

Reframing communication

Communicating and understanding wants and needs is an important aspect of behavior change management⁹. The following tips can help simplify communication with a person with dementia. Please see the module Communication for more guidance.

- Redirection may be more successful if it is multi-sensory, for instance pairing voice with touch. Observe individual and caregiver and suggest changes to the mode of communication based on their strengths and preferences.⁷
- Caregivers may find daily conversations easier if they *validate* the person's experience. Coach caregivers to focus on the emotion (e.g. fear, anger, etc.) rather than arguing about the inaccurate perceptions of reality. See the Communication module for more conversation tips. Some examples of validation include:

Instead of saying:

No, you don't go to bingo anymore.

Don't you remember when ... ?

You can't drive anymore.

You don't live with your mom, she died thirty years ago.

Try:

There's no bingo today.

I remember when ...

The car is in the shop, they'll call as soon as its done.

That sounds like a lovely arrangement.

Tips for caregivers' responses to hallucinations and delusions include:

- Responding in specific ways during a hallucination or delusion can decrease agitation and help calm the person.
- Don't argue or try to reason. Discuss the underlying emotion, which is usually fear or anger
- If the person is saying an important object is missing or has been stolen, try to search for the object. Then talk about another object you found, e.g. a photo album (distraction).
- Turn off the TV or computer when there are violent or upsetting programs or images.
- If the person is "hearing things" (auditory hallucinations), check for noises they could be misinterpreting. Also, consider changes in hearing including hearing loss, tinnitus, and proper use of hearing aides.
- If the person is "seeing things" (visual hallucinations), make sure there is adequate lighting. Look for shadows or reflections they could be misinterpreting. Cover or remove mirrors because they could think their reflection is a stranger.

Pharmacological treatments

Pharmacological treatments include antidepressants and anti-psychotics. Antidepressants have an important role if depression or anxiety underlies the behavioral symptom. Anti-psychotic use is common, but because of the high potential for harm, anti-psychotics should only be used when the benefits of the medication outweigh the potential harms of leaving the behaviors untreated. Some indications include:

1. If BPSD are significant enough to put the person with dementia or others at risk of harm
2. When BPSD are so significant the person with dementia can't participate or benefit from non-pharmacological interventions
3. When BPSD fails to respond to non-pharmacological interventions⁵

Pharmacological treatments usually require trial and error. The medications used to treat BPSD are not benign and have the potential to cause significant harm. For example, all anti-psychotic medications have a black box warning for use with older adults due to an increased risk of mortality¹⁰. Benzodiazepines are strongly associated with falls¹⁰. It is important to clearly communicate with the caregiver the potential risks of medications and the expected outcomes.

Care Plan Goals

1. Caregiver will identify one BPSD experienced now or in the past by the person with dementia.
2. Caregiver will state two factors that may have contributed to the BPSD.
3. Caregiver will describe one resource for managing BPSD.

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Communication Changes

Information for Home Health Clinicians

Communication Changes

Dementia will gradually affect a person's ability to communicate effectively. Communication refers to the ability to process and understand others and be understood by others. Intact cognitive functions are key to effective communication, especially those involving language. Dementia affects areas of the brain responsible for receiving, processing, and understanding information (receptive language) and remembering and responding to information (expressive language). There is also disruption in the ability to use and interpret non-verbal aspects of communication, such as gestures, tone of voice, turn-taking, and eye contact¹. Language deficits present as difficulties with word finding, forming complex sentences, and understanding conversation². Significant communication difficulties arise when these language deficits are combined with other dementia related deficits involving memory, attention, orientation, visuospatial skills, judgment, and insight³.

Failing to communicate effectively can cause emotional, physical, and social distress. For example, when a person with dementia is unable to express their needs or desires effectively, others may make decisions for them. This can lead to frustration, strained relationships, and diminished autonomy and well-being⁴. Communication deficits also put people with dementia at significant risk for elder abuse or neglect⁵.

Dementia Stage & Communication

In most types of dementia, language is reported to be among the first cognitive functions to be affected⁶. Communication becomes increasingly difficult as language impairment progresses over the course of dementia. The way in which communication changes varies from person to person and is influenced by the type and stage of dementia. For example, people with frontotemporal dementia often have more difficulty with language deficits compared to people with Alzheimer's dementia⁷. The following table outlines general communication changes that occur during each stage of dementia.

Communication Changes with Dementia Progression	
Dementia Stage	Communication Changes
Mild stage dementia	Difficulty with word finding when speaking or writing; Repeating oneself; Overwhelmed with excessive stimulation; Self-correct or apologize for communication errors.
Moderate stage dementia	Difficulty following conversations; Increased difficulty with word finding when speaking or writing; Describes familiar objects rather than call them by name; Difficulty following stories in books or movies; Difficulty following simple directions; Poor recall of recent events; Loss of factual knowledge; Increased use of gestures; Revert to speaking native language.
Severe stage dementia	Vocabulary is very limited; Difficulty understanding simple words; Talk or babble without meaning; Use non-verbal communication (e.g., facial expressions, vocal sounds).

(Alzheimer's Association, 2019⁷; Ripich, Wykle, & Niles, 1995⁸)

Assessment

Because the impact of dementia on communication varies from person to person, it is important assess each person's specific abilities and deficits. Assessment of communication is based on observation and history obtained from the patient when possible and family or other caregivers³. Assessment also includes consideration for possible underlying conditions contributing to communication changes, such as pain, infection, sensory deficits, medication side effects, or depression.

As dementia progresses, behaviors become a more frequent form of communication. Changes in tone, urgency, and speed of speech can signify an unmet need, such as hunger or thirst, pain, or loneliness. Non-verbal behaviors, such as agitation, restlessness, aggression, and combativeness, can also be an expression of an unmet need. Clinicians and caregivers should not dismiss these verbalizations and behaviors as symptoms of dementia, but rather try to determine the meaning of these behaviors (see Behavior Changes module).

Standardized measures of communication in people with dementia include the Arizona Battery of Communication Disorders (mild to moderate stage)⁹⁻¹⁰ and the Functional Linguistic Inventory (moderate to severe stage)¹⁰. In addition, the following questions can be used as a guide to identify communication deficits in a person with dementia and to tailor strategies for improving communication³.

Assess receptive abilities:

- *Can the patient understand a yes/no choice?*
- *Can the patient read simple instructions?*
- *Can the patient understand simple verbal instructions?*
- *Can the patient understand instructions given with physical cues?*
- *Can the patient make a choice when presented with two objects or options?*

Assess expressive abilities:

- *Does the patient have difficulty finding the correct word?*
- *Does the patient have difficulty creating sentences or a logical flow of ideas?*
- *Does the patient curse, use offensive or aggressive language, or exhibit aggressive or combative behaviors?*
- *Does the patient avoid verbalization altogether or mutter meaninglessly in various tones?*

Management

Effective communication is important for meeting basic and social needs¹¹. Education for caregivers about general communication strategies can make a significant impact on their communication patterns with the person with dementia¹¹. Caregiver education on communication strategies has been linked to maintaining abilities over time and improvement in

quality of life for the person with dementia. Further, when caregivers correctly use effective communication strategies, they experience lower levels of anxiety in their relationship with the person with dementia¹².

It can also be helpful to have an OT do a task analysis of a valued or challenging routine to help break it down for the caregiver and trial cueing modes and levels. Effective communication strategies include addressing physical, emotional, and environmental factors contributing to communication difficulties as well as caregiver approach to communicating with the person with dementia.

Communication Strategies

Environmental adjustments

- Reduce background noise (e.g. radios, TVs, hustle of busy environment, other's conversations)
- Adequate lighting

Effective listening

- Allow enough opportunities and time for the person to express themselves through verbal or non-verbal cues¹³
- Demonstrate interest in what they are communicating (e.g., maintain eye contact)
- Listen to find meaning in what the person is saying, and repeat to clarify
- Avoid correcting or criticizing
- Encourage non-verbal communication (e.g., pointing or gesturing) if having difficulty understanding what the person is trying to say

Simple and direct language

- Use common or more frequently used words
- Think about the words the person with dementia might use themselves
- Speak slowly, clearly and in direct presence of the person with dementia
- Use short words and sentences
- Avoid long sentences and multiple questions or instructions at once
- Consider using gestures, pictures, or written words if spoken words are confusing¹³

Simple choices

- Offering choices enables the person with dementia to retain a sense of control.
- As cognitive function declines, reduce the range in choices or ask yes or no questions.
- Example: Instead of asking "What would you like to drink?" ask "Would you like water or milk?" or "Would you like coffee?"

Model tasks

- Provide verbal cues step by step through a complex task (e.g. self-care). Depending on the person, the verbal cues may be reduced when completing the task in the future, which allows for increased independence in self-care or other activities¹⁴
- If visual-perceptual skills are intact, demonstrate the task or steps in the task to help the person with dementia understand what is being asked. Example: If the person is having difficulty brushing their hair, a caregiver may pick up the hairbrush, mime brushing their hair, then hand it to the person with dementia and prompt "you try."

Reorient

- Reorientation is cuing the person with dementia to reality, including person, place, time, and situation.
- Consider how important reorientation is in specific circumstances and forecast what the likely reaction will be to the reorientation attempt, such as will it soothe, irritate, sadden, or diminish self-esteem.
- If reorientation will sadden, anger, or diminish self-esteem, consider another communication method.
- Examples:
 - Person with dementia: *How are my parents doing?*
 - Caregiver: *Your parents died a long time ago. You are 86, and your parents could not possibly be alive.*
- Example:
 - Person with dementia: *I want to go for a drive. Where is my car?*
 - Caregiver: *You sold your car years ago. You do not have a car anymore.*

Compassionate fibbing

- Consider if entering into a person's lived reality will reduce anxiety or agitation and provide a better sense of emotional wellbeing.
- Examples:
 - Person with dementia: *How are my parents doing?*
 - Caregiver: *Your parents are fine. They are at church right now.*
 - Person with dementia: *I want to go for a drive. Where is my car?*
 - Caregiver: *The car is in the shop. It will be ready next week.*

Acknowledgment

- Understand the person's view of the world without entering into it or challenging it. Rather, acknowledge the person's feelings and discuss those feelings.
- Example:
 - Person with dementia: *How are my parents doing?*
 - Caregiver: *It sounds like you are thinking about your parents. Tell me about them.*
 - Person with dementia: *I want to go for a drive. Where is my car?*
 - Caregiver: *You must be thinking about your car today. Tell me about your car. What kind of car is it? Did you go for long trips in your car?*

Reflection

- Questions for the caregiver to consider: What happened? What did I do? What would I do differently next time?

Care Plan Goals

1. Caregiver will identify one communication change experienced by the person with dementia
2. Caregiver will state one environmental strategy for improving communication with the person with dementia.
3. Caregiver will describe one communication strategy for improving communication with the person with dementia.

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Hospice and Palliative Care Information for Home Health Clinicians

Hospice and Palliative Care

Dementia is a progressive condition for which there is no cure. On average, people with dementia live 4.5 years after diagnosis¹. The most common cause of dementia, Alzheimer's disease, was the 5th leading cause of death in the United States in 2016². In the last year of life, people living with dementia are often unable to recognize family members, walk independently, incontinent of urine and stool, unable to perform any activities of daily living, and have minimal speech³. In a study of nursing home residents, the last year of life was characterized by medical complications including swallowing problems, fevers, and pneumonia⁴. Furthermore, people living with dementia often experience distressing symptoms such as pain and shortness of breath⁴. Most, if not all, people with severe dementia could benefit from palliative and hospice care to help relieve distressing symptoms. Unfortunately, many people living with dementia often do not have the opportunity to benefit from expert symptom management and end of life care that palliative and hospice care provide. In 2015, just 16.5% of patients enrolled in hospice had a diagnosis of dementia⁵.

Palliative Care

Palliative care is a medical specialty for the care of people with a serious illness with a goal of improving the quality of life for both patients and their families. The focus of palliative care is team-based symptom management. There is no cure for Alzheimer's disease and other dementias, but patients receiving palliative care can pursue treatment for comorbid conditions along with palliative care. Palliative care is appropriate at any point in the illness course of a person with dementia, from the moment of diagnosis until end of life. The focus on palliation and symptom management becomes more and more important as the disease progresses to moderate and then severe stages. Reducing pain and distressing symptoms, and maximizing comfort, should be the focus of care at later stages.

Hospice Care

Hospice is a philosophy of care for people with a terminal diagnosis that shifts the focus of care away from curing the disease, and onto treating the person's symptoms and addressing emotional and spiritual needs of patients and caregivers. Hospice care is a benefit covered by Medicare Part A and other payers. To enroll in hospice, the physician or hospice medical director must certify that the person is terminally ill, and the person or his/her surrogate decision-maker must choose to receive hospice care, thereby waiving the right for Medicare to pay for any other services to treat the terminal illness⁶.

Minimizing hospitalization and aggressive diagnostics and treatments is an appropriate goal for people with severe dementia. From observational studies, we know that patients with severe dementia who are enrolled in hospice are less likely to die in the hospital and are less likely to have been hospitalized in the 30 days prior to their death³. In addition, when enrolled in hospice, people with severe dementia are more likely to receive treatment for pain and dyspnea and their families report greater satisfaction with care³.

Home Health Clinicians play a crucial role in end of life care for people with dementia.

Hospice care should be considered for patients who score between 20 and 30 on the Quick Dementia Rating Scale (QDRS).

The following are some characteristics of people in the severe stage of dementia:

- Inability to recognize family members
- Delusions, anxiety, agitation
- Remembering few if any details of childhood or early life
- Inability to walk
- Inability to speak
- Incontinence of bowel and bladder

The home health team can advocate for a hospice consult from the primary care provider, and provide services within their scopes to support caregivers. Before the patient reaches the severe stage, the home care nurse should discuss hospice as part of a conversation regarding patient and family's wishes, goals of care, helping the family plan to focus on comfort as dementia progresses towards end of life. This may help normalize the transition to hospice care and reinforce the terminal nature of the disease. When a patient is in the severe stage, it can be helpful for a social worker to discuss the financial benefits and implications of hospice care with families.

Therapists can also support caregivers by teaching safe transfer techniques, hygiene assistance, and focusing on meaningful time spent with the loved one. For those family members who want to keep the person with dementia in the home at end-of-life, the additional support of hospice services may be key to honoring that wish. The home health team can be instrumental in ensuring patients with dementia receive optimal end of life care by keeping the lines of communication open regarding hospice care and making appropriate referrals as the disease progresses.

Care Plan Goals

1. The caregiver will be able to name two benefits of hospice care.
2. The caregiver will be able to describe how to enroll in hospice care.

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Resources—Getting Help

Information for Home Health Clinicians

Resources—Getting Help

The purpose of this section is to help the caregiver identify resources, both professional and social, for a variety of potential situations. Older adults often have multiple health care providers between primary and specialty care. It can be confusing to know who to call when a specific symptom presents. Even when the caregiver identifies the provider to call, it can be challenging to reach the person who can be the most helpful in solving the problem. When a person is receiving home health services, the home health clinician(s) will be a resource. However, the home health clinician(s) will not be in the home indefinitely. As you go through this section with the caregiver, he or she will create an individualized list of resources so when a problem does arise, the caregiver will know who to call. This resource list will be referenced in other modules as you review with the caregiver who to call if there is a fall, for example.

Assessment

Assess for home support systems:

- If others are living in the home, are they a source of support? Do they work? Are they available to help?
- Who does the caregiver rely on — friends, siblings, extended family members, co-workers, children, neighbors, church groups?
- If there are people the caregiver identifies as helpers, are those individuals able and willing to help?
- Is the support system stable at this time?
- Are there any paid caregivers in the home? What agency do they work for? How many hours are they present and what tasks do they do? Is the family caregiver happy with how they work with the person with dementia?
- Does the patient have a Personal Response System (such as Lifeline)?

Assess for community support:

- Is the person with dementia enrolled in a Managed Care Organization (MCO) – for example CareWI?
- Does the individual attend adult day care?
- Is a Dementia Care Specialist (DCS) from the state involved?
- Has the person or caregiver been in touch with the Aging and Disability Resource Center (ADRC)?
- Is the individual receiving Meals on Wheels?
- Does the individual attend an Adult Day Center? If so, what services does the center provide?

Assess for the need for a medical referral such as:

- Complex case management program
- Acute Care for the Elderly (ACE) if there is a readmission to the hospital
- Transition to a geriatrician or geriatric clinic as the primary care provider
- Memory clinic evaluation
- Specialists depending on comorbid medical conditions or new symptoms

Resources for People Living with Dementia and Their Caregivers in the Greater Madison Area

As you prepare to discharge the person with dementia from home health, consider what resources the person and their caregiver will need to avoid stress, injury, adverse health outcomes, emergency medical visits, and hospitalizations. When an individual has moderate to severe dementia, functional and health status can decline rapidly. Behavioral and psychological symptoms of dementia can change from day to day. The emotional stress and physical burdens of caregiving can be immobilizing or cause a crisis. Consider a warm hand-off to a dementia care specialist or other support system for the person with dementia and caregiver prior to discharge. Even if the caregiver does not immediately need the services, a connection will help ensure support if it is needed in the future. The home health social worker is an expert in local resources and can connect families to them.

Aging and Disability Resource Center

Dementia Care Specialist for Dane County

2865 N. Sherman Ave., Madison, WI 53704

Phone: 608-240-7400 | Web: www.daneadrc.org

Services: Respite and funding assistance, Memory Care Connections (see flyer), adult day care options: www.dhs.wisconsin.gov/guide/adcdane.pdf, Senior Care Management services

Wisconsin Institute for Healthy Aging – Powerful Tools for Caregivers (see flyer)

1414 MacArthur Rd., Suite B, Madison, WI 53714

Phone: 608-243-5690 | Email: info@wihealthyaging.org | Web: www.wihealthyaging.org/

Alzheimer's and Dementia Alliance of Wisconsin

3330 University Ave #300, Madison, WI 53705

Phone: 608-232-3400 or 888-308-6251 | Email: support@alzwissc.org | Web: www.alzwissc.org

Services: Support groups, memory cafes, one-on-one consultation, educational programs

Alzheimer's Association

Madison Office, 2820 Walton Commons West, Suite 132, Madison, WI 53718

Phone: 608-203-8500 | 24/7 Helpline: 1-800-272-3900 | Web: www.alz.org

Care Plan Goals

1. Caregiver will have effective long-range plan in place.
2. Appropriate community services will be involved for ongoing patient/caregiver support.

Dementia Basics

TEACH BACK

What are two characteristics of the moderate stage of dementia?

1. _____

2. _____

TEACH BACK

What are two characteristics of the severe stage of dementia?

1. _____

2. _____

TEACH BACK

What is key to preventing hospitalization when a person with dementia begins to suffer a medical complication?

Caregiver Role Strain

TEACH BACK

How would you describe caregiver role strain in your own words?

TEACH BACK

What are two ways to reduce caregiver role strain?

1. _____

2. _____

Falls

TEACH BACK

Consider the person with dementia who you care for. What are two things about that person that increase the risk for a fall?

1. _____
2. _____

TEACH BACK

What are two changes you could make to the environment or to how you give care to your loved one that might prevent a fall?

1. _____
2. _____

TEACH BACK

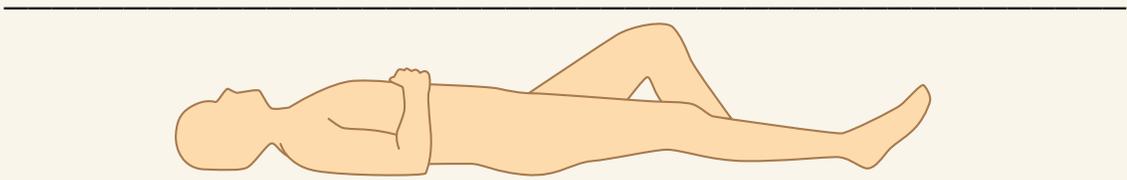
Name two things you should tell the health care provider about the circumstance of a fall:

1. _____
2. _____

Pressure Injuries

TEACH BACK

Where on the body are pressure injuries most likely to develop?



TEACH BACK

Describe what an early pressure injury looks like:

TEACH BACK

What are two ways pressure injuries can be prevented?

TEACH BACK

What are two ways pressure injuries are managed or treated?

Weight Loss

TEACH BACK

What are two ways weight loss can be prevented?

1. _____

2. _____

TEACH BACK

What are two ways weight loss can be managed?

1. _____

2. _____

Swallowing Problems

TEACH BACK

What is one way to prevent swallowing problems?

TEACH BACK

What is one sign of a swallowing problem?

TEACH BACK

What should you do if you notice a problem swallowing?

TEACH BACK

What is one way to manage swallowing difficulties?

Pneumonia

TEACH BACK

What are two things you can do to help prevent pneumonia in someone with dementia who you care for?

1. _____
2. _____

TEACH BACK

What are two signs of pneumonia in someone who has dementia?

1. _____
2. _____

TEACH BACK

Name two ways pneumonia can be treated at home to avoid a hospitalization?

1. _____
2. _____

Incontinence

TEACH BACK

What are two things you can do to help prevent urinary incontinence in the person you care for?

1. _____
2. _____

TEACH BACK

What are two signs of urinary incontinence that would cause you to notify the primary care provider?

1. _____
2. _____

TEACH BACK

Name two ways urinary incontinence can be managed.

1. _____
2. _____

Constipation

TEACH BACK

What are two things you can do to help prevent constipation in the person you care for?

1. _____
2. _____

TEACH BACK

What are two signs of constipation in someone who has dementia?

1. _____
2. _____

TEACH BACK

Name two ways constipation can be managed.

1. _____
2. _____

Pain

TEACH BACK

What are two things you can do to help prevent pain in the person you care for?

1. _____
2. _____

TEACH BACK

What are two signs of pain in a person who has dementia?

1. _____
2. _____

TEACH BACK

Name two ways to manage pain in a person who has dementia.

1. _____
2. _____

Infection

TEACH BACK

What is one action you can take to help prevent an infection?

TEACH BACK

What are two signs that may mean the person you care for has an infection?

1. _____

2. _____

TEACH BACK

What should you do if you suspect the person you care for may have an infection?

Dehydration

TEACH BACK

What are two things you can do to help prevent dehydration in the person you care for?

1. _____
2. _____

TEACH BACK

What are two signs of dehydration in someone who has dementia?

1. _____
2. _____

TEACH BACK

Name two ways to manage dehydration in a person who has dementia.

1. _____
2. _____

Behavior Changes

TEACH BACK

When you think of your loved one, has that person experienced any of these challenging behaviors? What was it?

TEACH BACK

Think of the challenging behavior you have witnessed in the past. Can you think of any factors that may have contributed to the behavior of your loved one?

TEACH BACK

What is one resource for managing the behavioral and psychological symptoms of dementia?

Communication Changes

TEACH BACK

When you think of you the person you care for, has that person experienced a change in their ability to communicate? If so, what changes have they experienced?

TEACH BACK

What is one change you can make when you are talking to a person with dementia?

Hospice and Palliative Care

TEACH BACK

What are two benefits of hospice care?

1. _____
2. _____

TEACH BACK

How is a person enrolled in hospice care?
