

This Agrace reference is intended as a guide and resource for clinicians caring for patients with dementia/Alzheimer’s disease.

Please contact the Agrace Clinical Education Team if you have any questions about this content.

Clinical Practice Guidelines: **Palliative Management of Dementia**

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Dementia at a Glance

Dementia is a neurocognitive disorder characterized by dysfunction or loss of memory, orientation, attention, language, judgement and reasoning (Lewis et al., 2017). About 15 percent of Americans have dementia, and an estimated 60 to 80 percent of people with dementia have a diagnosis of Alzheimer’s disease, which can only be definitively diagnosed after death (Lewis et al., 2017).

Alzheimer’s disease attacks indiscriminately. It strikes men and women, people of various ethnicities, rich and poor, and people with varying degrees of intelligence (Varcarolis & Halter, 2018). Dementia describes a group of symptoms, typically caused by a disease or condition, which includes memory, communication and language, focus, reasoning and judgement and visual perception. At least two of these symptoms must be present for a diagnosis of dementia (Alzheimer’s Association, 2018).

From August 2018 to August 2019, 35 to 40 percent of the hospice patients Agrace served every day had dementia as a primary or secondary diagnosis. Patients with a dementia diagnosis are on service 151 days, on average. A patient without a dementia diagnosis is on Agrace’s hospice services for an average of 84 days.

The incidence of dementia increases with age, which is the greatest risk factor. **Severe memory loss is not a normal part of growing older.** Mild cognitive impairment (MCI), the stage of cognitive decline due to normal aging and dementia, is a risk factor for developing dementia. Symptoms include issues with memory, language and thinking/judgment (Dementia Capable Wisconsin, n.d.). Mild cognitive impairment is not necessarily progressive and does not affect daily activities of living as compared to dementia (Dementia Capable Wisconsin, n.d.).

The exact cause of dementia is unknown, but it is likely a combination of factors. This can include a familial or genetic link. Lifestyle factors associated with cardiovascular disease, such as inactivity, high cholesterol, diabetes and obesity are all risk factors for Alzheimer’s disease, one of many diseases that have a dementia component. Brain injury and trauma are associated with a greater risk of developing Alzheimer’s disease and other dementias. Brain health, in general, is affected by modifiable factors such as remaining mentally and socially active and consuming a healthy diet (Varcarolis et al., 2018). Regarding lifestyle factors, “what is good for your heart is good for your head,” including physical activity (Braus, A., 2018). Again, dementia is not a part of the normal aging process.

Alzheimer’s disease is the only cause of death among the top 10 in the United States that cannot be prevented or cured. For people with Alzheimer’s disease, the burden of care on the family, caregivers and society is staggering and has often been referred to as the “long goodbye” or “death in slow motion” (Lewis et al., 2017).



Empathy

Patients with dementia are still people—with the basic human needs of dignity, respect and comfort. As part of the disease process, the patient’s personality may change. They may become more self-absorbed, not realizing the impact they are having on others. They are likely to go backwards in moral development and lose values they held throughout their lives (Robbins, K., 2019). Before interacting with a patient with dementia, stop yourself and check your demeanor. Let go of the idea there is logic behind the actions of a person with dementia. You cannot explain the situation logically and expect the patient living with dementia will accept it (Snow, T., n.d.).

Person-centered approach: As with all patients, care for people with dementia should be *person-centered*, and decisions should include their input whenever possible. Take time to learn about the patient. Obtain their personal history, likes and dislikes, abilities (to promote independence), emotional memories (sights, smells, sounds, music, relationships), and possible triggers—not just physical ones (Alzheimer’s Association, 2019). This information is important to providing high-quality care for the patient and insight to their behaviors.

Different Types of Dementia

When describing a person’s cognitive impairment, remember there are many types of dementia in addition to Alzheimer’s disease. Mislabeling a patient’s condition can be upsetting to them and/or their loved ones. Below is information on the types of dementia that Agrace patients may be experiencing.

Alzheimer’s dementia

- **Causes:** Plaques (beta amyloid protein clumps) and tangles (tau protein tangles). Gene mutations, genetic, lifestyle and environmental factors increase risk of developing Alzheimer’s. (Dementia — Symptoms and Causes, 2019)
- **Symptoms:** Persistent memory loss, difficulty with problem solving, focus, decision making, executive functions and behavioral control as well as personality changes. (Alzheimer’s Disease, 2018)
- **Prevalence:** It is the most common type of dementia, accounting for 60 to 80 percent of dementia diagnoses. (Alzheimer’s Association, 2018)

Vascular dementia

- **Causes:** Damage to blood vessels in the brain. Patients can experience stroke or other damage to brain (Dementia — Symptoms and Causes, 2019).
- **Symptoms:** Slowed thinking, increased difficulty with problem-solving, focus and reasoning. These symptoms are more prevalent than memory loss (Dementia—Symptoms and Causes, 2019). Depression is a common comorbidity (Braus, A., 2019).
- **Prevalence:** Of all dementias, 10 to 15 percent are mixed vascular; only 5 to 10 percent are pure vascular (Braus, A., 2019).

Fronto-temporal dementia

- **Causes:** Degeneration of nerve cells in the frontal and temporal regions of the brain (Dementia—Symptoms and Causes, 2019).
- **Symptoms:** Deficits can include executive functions, apathy, judgment, insight, behavioral control, personality change, memory, learning (Braus, T, 2019).
- **Prevalence:** Five to 10 percent of all dementias are fronto-temporal (Braus, T, 2019).

Lewy Body dementia

- **Causes:** Protein in brain formed in balloon-like clusters (Dementia—Symptoms and Causes, 2019).
- **Symptoms:** Early symptoms can include gait or balance disturbance, hallucinations, sleep disturbance, falls, visual processing. Later symptoms can include bradykinesia (rigidity or slowing), unresponsive episodes, increased sleeping, and severe impairment in speech and memory. Weight loss and immobility play a big role in predicting hospice eligibility (Braus, T, 2019).
- **Prevalence:** Five to 10 percent of all dementias (Dementia with Lewy Bodies, n.d.).

Parkinson’s dementia

- **Causes:** Protein in brain formed in balloon-like clusters as in Lewy Body dementia (Parkinson’s Disease Dementia, n.d.).
- **Symptoms:** Memory, concentration and judgment impairments; stifled speech; sleep disturbances; increased daytime sleepiness; visual hallucinations; paranoid ideas; irritability; anxiety (Parkinson’s Disease Dementia, n.d.).
- **Prevalence:** Two percent of all people over 65 years of age have Parkinson’s disease; 50 to 80 percent of people with Parkinson’s have experienced dementia symptoms (Parkinson’s Disease Dementia, n.d.).

Other dementias

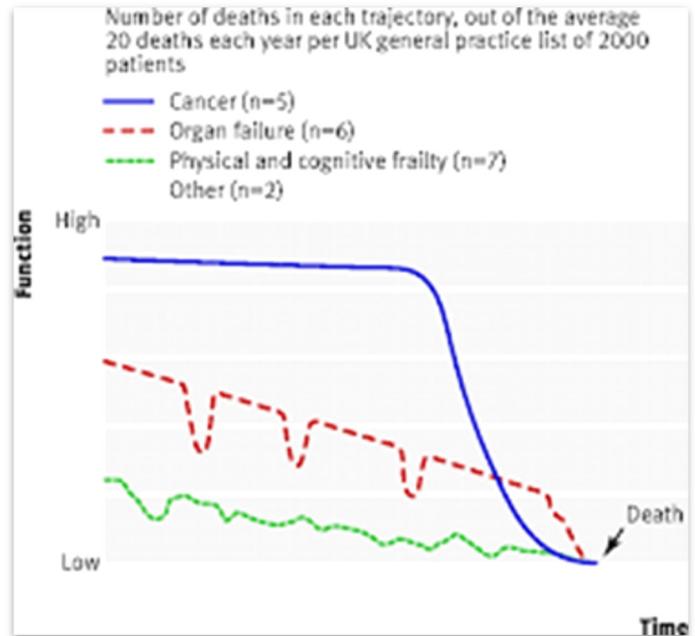
There are more than 120 types of dementia (Snow, T., n.d.). Agrace staff need to be aware of other dementias and understand that symptoms vary from one type to the next:

Genetic syndromes	ETOH (ethyl alcohol) related
Infection	White matter diseases
Depression	Exposure to toxins
Huntington’s disease	Creutzfeldt-Jakob disease
Progressive supranuclear dementia	

Before Palliative or Hospice Care

Pathologic changes often precede clinical signs of dementia by anywhere from 5 to 20 years. The rate of progression from mild to severe dementia is highly variable and can range from 3 to 20 years. The loss of intellectual ability is gradual and irreversible.

On the graph at right, the green line represents those with cognitive frailty (dementia). Compared to other terminal diagnoses, dementia has a long, slow decline. Additionally, when someone is hospice-appropriate with dementia, they usually have been functioning at a very low level for a while before starting services. This means that they may have increased needs, as may their caregivers, due to the level of continual support needed over a much longer period of time.



Source: Murray, S.A.

Stages of Alzheimer’s Disease and Hallmarks

(Varcarolis et al., Table 23.3, 2018)

The stages of Alzheimer’s go from mild to moderate to severe.

Mild Alzheimer’s Disease (early-stage)

The person and their loved ones notice memory lapses. The person may still be able to function independently but will experience issues like these:

- Difficulty retrieving correct words or names previously known
- Trouble remembering names when introduced to new people,
- Greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Trouble with planning or organizing

Moderate Alzheimer’s Disease (middle-stage)

The person confuses words, gets frustrated or angry, or acts in unexpected ways such as refusing to bathe. Symptoms become noticeable to others. The person may:

- forget events or own personal history;
- become moody or withdrawn, especially in socially or mentally challenging situations ;
- be unable to recall their own address or telephone number;
- become confused about where they are or what day it is;
- need help choosing proper clothing for the season or the occasion;
- have trouble controlling bladder and bowels;
- change sleep patterns, such as sleeping during the day and becoming restless at night;
- be at risk wandering and becoming lost; or
- become suspicious, delusional or compulsive.

Severe Alzheimer’s Disease (late-stage)

The person loses the ability to respond to their environment, carry on conversation and, eventually, control movement. They may still say words or phrases, but communicating pain becomes difficult. The person may:

- have a change in personality;
- require full-time, around-the-clock assistance;
- lose awareness of recent experiences and of their surroundings;
- require high levels of help with daily activities and personal care;
- have changes in physical abilities, including ability to walk, sit and eventually, swallow;
- have increasing difficulty communicating; and
- become vulnerable to infections, especially pneumonia.

A Note on End-of-Life Care for Dementia Patients

People with dementia who are reaching end of life may still be able to make choices about their care. As much as possible, patients should be included in decision-making.

People with severe dementia often communicate through their behaviors, which include their reactions to care (Alzheimer’s Association, 2009). Clinicians need to understand a patient’s behavior symptoms and communicate with them using methods they will understand, such as gentle touch, direct eye contact, smiling and a pleasant tone of voice. It is important for clinicians to minimize the person’s physical, emotional and spiritual distress while maximizing comfort and well-being (Alzheimer’s Association, 2009).

It can be challenging to identify the end-of-life phase in people with dementia, as their symptoms may have an unpredictable trajectory. Clinicians should learn how to ensure that extreme symptoms are avoided or alleviated, and to recognize the main areas of need for the individual, which may include communication, pain, dietary and fluid intake, and infections (Regan et al., 2014).

Hospice Eligibility

According to CMS guidelines for hospice eligibility, patients with a primary diagnosis of dementia are considered terminal (life expectancy of six months or less) if they meet the following criteria, (1 and 2 should be present):

1. Stage 7A or beyond according to the Functional Assessment Staging Scale (FAST) (*see below*) with all the following:
 - a. Inability to ambulate without assistance
 - b. Inability to dress without assistance
 - c. Urinary and fecal incontinence, intermittent or constant
 - d. No consistent meaningful/reality-based verbal communication, or the ability to speak is limited to a few intelligible words

2. Has had at least one of the following conditions within the past 12 months:
 - a. Aspiration pneumonia
 - b. Pyelonephritis or other upper urinary tract infection
 - c. Septicemia
 - d. Pressure ulcers, multiple and/or Stage 3 or Stage 4
 - e. Fever, recurrent after antibiotics
 - f. Inability to maintain sufficient fluid and caloric intake demonstrated by either:
 1. 10% weight loss during the previous six monthsOR
 2. Serum albumin < 2.5 gm/dl

Of note, the FAST scale is used for Alzheimer's dementia only, as it follows the FAST progression. Other dementias do not track in the same linear fashion. Major neurocognitive disorder or senile degeneration of the brain may be used for hospice diagnosis if the patient does not have a formal or specific dementia diagnosis.

Functional Assessment Staging (FAST)

Check highest consecutive level of disability:

1. No difficulty either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.*

4. Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty shopping, etc.*
5. Requires assistance in choosing proper clothing to wear for the day, season, or occasion, e.g., patient may wear the same clothing repeatedly unless supervised.*
6.
 - a. Improperly putting on clothes without assistance or cueing (e.g., may put street clothes on overnight clothes, or put shoes on the wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.*
 - b. Unable to bathe properly (e.g., difficulty adjusting the bath-water temperature) occasionally or more frequently over the past weeks.*
 - c. Inability to handle mechanisms of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
 - d. Urinary incontinence (occasionally or more frequently over the past weeks).*
 - e. Fecal incontinence (occasionally or more frequently over the past weeks).*
7.
 - a. Ability to speak limited to approximately half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.
 - b. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
 - c. Ambulatory ability is lost (cannot walk without personal assistance).
 - d. Cannot sit up without assistance, e.g., the individual will fall over if there are not lateral armrests on the chair.
 - e. Loss of ability to smile.
 - f. Loss of ability to hold head up independently.

**Scored primarily based on information obtained from knowledgeable information and/or category. Reisberg, B. Functional Assessment Staging (FAST). Psychopharmacology Bulletin 1988; 24:653-659*

Soft Signs of Decline

Soft signs of decline can also be a factor in hospice eligibility. Quantify findings as much as possible. Compare and chart findings 3 to 6 months ago, as compared with current:

- **Changes in speech:** Are they speaking less? How many words? Repetition?
- **Ability to get up from a chair:** Can they do it alone or assisted? Do they have increased shortness of breath, need more tries etc.?)
- **Changes in dressing:** Are they staying in pajamas now? If dressing, need assistance?
- **Going out:** Did they leave their home before, but are doing so less now or not at all?
- **Changes in sleeping:** Spending more time sleeping during the daytime?
(For example, 3 – 6 months ago, the patient was sleeping 16 hours per day. Now they sleep 20 hours per day.)



- **Changes in hygiene:** Have there been changes in the patient's ability to bathe? Have they changed from showering to having a bed bath?
- **Changes in skin:** Any new skin breakdown or worsening of existing wounds?
- **Falls:** Have there been any falls? Falls with injuries?
- **Changes in eating:**
 - Have they started drinking a protein shake?
 - Has their diet consistency changed?
 - Have they stopped using utensils?
 - Do they need reminders or need to be fed?
 - Are they coughing when eating or drinking now?
 - Are they eating less or taking longer to eat?



- **Changes in weight:** Always document arm circumference (always in centimeters!) and weight, if patient can be weighed.
- **Changes in pain:**
 - Is there new pain or another new pain location?
 - Have there been any changes in pain medications?
 - Are they using more pain medication? Higher doses? More PRNs?



- **Changes in breathing:**

- Is shortness of breath getting worse?
- How far can they walk before getting short of breath now compared to 2 months ago?
- What other activities cause dyspnea? Eating? Talking?
- Are they using oxygen now?
- Has oxygen use increased? Document using a higher amount: "from 2 to 4 liters," or more often: "Now using oxygen 24/7; used to be only at night."



- **Changes with medical equipment:**

- Has there been addition of DME?
- Have they used a walker, cane, wheelchair or Broda chair in past 3 to 6 months?
- Is more assistance or a new device needed for transfers now?

- **Have there been any visits to the ER or admissions to the hospital?**

- **Do they have any other symptoms that would suggest progression of comorbid diseases?**

- **What is their level of alertness as compared to 2 months ago?**

- Could they recognize family and care givers 3 months ago but not now?
- Are they still following instructions like "raise your arms"?

- **Has there been a decrease in [PPS](#) (Palliative Performance Scale) or FAST scores?**

Of note: persons with Alzheimer's were hospitalized for pneumonia or hip fracture, half died within six months (Morrison, 2000).

Senile Degeneration of the Brain

If the person does not have a specific dementia diagnosis, there are several diagnoses that may be entered for hospice eligibility, including these:

- dementia, not otherwise specified
- dementia with behaviors
- dementia without behaviors
- senile degeneration of the brain

There is a high prevalence of non-specified dementia subtype diagnosis; it is difficult for providers to make a specific dementia diagnosis in a clinical setting (Goodman et al., 2017).

Delirium vs. Dementia: The Differences

Delirium is a state of temporary, but acute, mental confusion. The start of delirium is usually rapid, within hours or a few days. In many cases, delirium is preventable and/or reversible (unlike dementia, which is irreversible) (Lewis et al., 2017). Individuals at the end of life are at a high risk for developing delirium, with prevalence rates comparable with hospitalized elders and critically ill adults (Journal of Hospice & Palliative Nursing, 2016).

SYMPTOM	DELIRIUM	DEMENCIA
Consciousness	Decreased or hyper	Alert
Orientation	Disorganized	Disoriented
Course	Fluctuating	Steady, slow decline
Attention	Impaired	Impaired
Onset	Acute	Chronic
Psychomotor	Agitated or lethargic	Usually normal
Hallucinations	Perceptual	Usually not present
Sleep wake	Abnormal	Usually normal
Speech	Slow, incoherent	Aphasic, word finding

Tucker and Ferry, 2014

Knowing what can lead to delirium helps determine effective interventions. A way to remember reversible causes of delirium is using the CHIMBOP acronym.

CHIMBOP Reversible Causes of Delirium	
C	Constipation
H	Hypovolemia, hypoglycemia
I	Infection
M	Medications
B	Bladder catheter or outlet obstruction
O	Oxygen deficiency
P	Pain

Journal of Hospice & Palliative Nursing, 2016

Symptom Management in End-of-life Dementia Patients

The following issues are common in people with dementia toward end of life. The role of the hospice/palliative care clinician is to teach patients and families about these issues, normalize them when they occur, and offer strategies to help them anticipate and prepare for changes as the end of life nears.

Communication

Like every other human being, people with dementia need social interaction. Communication becomes more difficult as the dementia progresses, because both the expressive and receptive language abilities are affected (Regan et al., 2014). Relying only on verbal communication will limit understanding of what the patient is trying to communicate. A clinician's ability to listen, interpret and communicate effectively affects the quality of their care (Regan et al., 2014).

Caregivers or clinicians may be concerned by behaviors of dementia patients. In people who can no longer use words or complex language, verbal or physical aggression may be an attempt to communicate unmet needs (Regan et al., 2014). Validate the emotions expressed, no matter how out of context they may seem. Accept the person with the dementia's reality and respond on an emotional level (Regan et al., 2014).

Responding to someone's emotional level includes mirroring the emotion that you are seeing in both words and actions. For example, if a person with dementia is crying, saying, "I'm sorry that you feel sad," while frowning and offering a tissue helps to link your actions and their emotions together. Since a person living with dementia often has impaired communication skills, it is the job of the caregiver to help add meaning to actions, words and the environment.

Care Considerations

- Nonverbal signals from the caregiver or clinician, through gestures, body language, facial expressions and touch, can help enhance communication; they will hinder if there is a mismatch between verbal and nonverbal communication.
- Use short sentences.
- Use yes or no questions.
- Meet the patient at eye level.
- Offer appropriate physical contact, such as holding hands or a hug, to reassure trust.
- Maintain eye contact as much as possible.
- Take time to look for nonverbal signs from the patient, such as facial grimacing, skin picking, clenching of hands.
- Talk with the patient, even if you don't think they can follow what you are saying.
- Talk about things of interest to the person, or reminisce about the past.

(Alzheimer's Society, 2017)

Pain

People with dementia often will have difficulty expressing pain, so it is challenging to assess it and discuss treatments. When their ability to communicate verbally declines, people with dementia will rely on nonverbal communication, which may include challenging behaviors. These behaviors can often lead to the inappropriate use of psychotropic medications (Alzheimer’s Association, 2009).

Fifty percent of people with dementia regularly experience pain. (Kooten, et al, 2015). McCarthy, et al (1997) found that pain was more commonly experienced by people with dementia than by people with cancer.

Unrelieved pain in dementia patients can lead to behavioral changes, including social withdrawal, lack of sleep, agitation, irritability and aggression (Regan et al., 2014).

Care Considerations

- Rather than being a symptom of dementia, behaviors such as shouting, agitation and restlessness may be a sign that a person is in pain or discomfort.
- Remember, pain is the “fifth” vital sign.
- Know the patient; there may be certain things a patient does when they are in pain.
- Look for facial grimacing and other nonverbal signals, such as tenseness, rolling back and forth or pulling at a part of the body.
- Help make the person comfortable with gentle exercise, massage, aromatherapy or warm packs.
- Check to see if patient is too hot or too cold.
- Provide a calm and supportive environment.
- Assess for anxiety or try to determine if the patient is upset.

(Alzheimer’s Society, 2017)



Pain Assessment IN Advanced Dementia (PAINAD tool)

(Warden, Hurley, Volicer, 2003)

Instructions:

- Assess the patient both at rest and during activity or with movement.
- Monitor changes in the total score over time and in response to treatment to determine if there were changes in pain.
- Note the patient's **comfort goal** on the care plan to use for evaluation of pain, charting purposes and the effectiveness of interventions.
- Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items); a higher score indicates more severe pain (0 = no pain to 10 = severe pain).

ITEM	0	1	2	SCORE
Breathing independent of vocalization	Normal	Occasional labored breathing or hyperventilation	Noisy, labored breathing Long periods of hyperventilation Cheyne-stokes respirations	
Negative vocalization	None	Occasional moan or groan Low-level of speech with a negative or disapproving quality	Repeated troubled calling out Loud moaning or groaning Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frowning	Facial grimacing	
Body language	Relaxed	Tense Distressed pacing Fidgeting	Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
TOTAL				

Eating and Drinking

Eating and drinking become complex. Decisions related to eating and drinking can become ethically challenging when a patient with dementia reaches end of life. Swallowing issues are a common reason for reduced intake and malnutrition. Swallowing issues can increase risk for aspiration pneumonia and may signal the end-of-life phase in a dementia patient. Patients with dementia may also eat and drink less due to reduced appetite, less enjoyment of food, increased sleep or agitation, and undetected discomfort (Regan et al., 2014)

A person with dementia may refuse to eat or drink because of physical or emotional conditions at end of life. It is normal for a person approaching end of life to no longer be able to take in food and fluid normally by mouth (Alzheimer's Society, 2017). People do not need as many calories when they are dying. Eating and drinking can cause discomfort, and our only obligation as clinicians is to offer food or drink.

Care Considerations

- Assess the need for soft food or thickened fluids to help prevent choking.
- Offer thin liquids if it is the patient's/family's preference to continue to take fluids by mouth.
- Have the person sit upright when eating or drinking.
- Offer nutrient-dense foods to maximize the quality of the intake (Alzheimer's Association, 2009).
- Always offer food or fluids, even if it is just mouthful or sips.
- Make sure the person's mouth feels comfortable:
 - Provide sips of chilled water or juice.
 - Offer ice cubes for the person to suck on.
 - Keep the patient's lips moist and clean by swabbing.
 - Apply lip balm.
- Teach caregivers/family about nutrition and hydration at end of life, if needed.
- Teach about giving only one food at a time, as dementia patients will eat and drink if they have fewer choices (Alzheimer's Association, 2009).

Infections

People in the later stages of dementia are at risk for infection, especially urinary tract infections or chest infections such as pneumonia. Often the infections are caused by lower fluid intake, swallowing problems and reduced mobility (Alzheimer's Society, 2017). Such infections are often the cause of death in many patients with Alzheimer's disease (Lewis et al., 2017).

Care Considerations

- Keep the patient hydrated, dependent on their comfort and goals.
- If patient is immobile, turn them often.
- Promote deep breathing and coughing or use incentive spirometer, if available, to prevent pneumonia.
- Use proper hand hygiene and use gloves, when needed.
- Assess for any signs of infection, including change in behavior, fever, cough (pneumonia, or pain on urination). (Lewis et al., 2017)

Behaviors

Behavioral concerns occur in about 90 percent of patients with Alzheimer’s disease, but can also occur in people living with other types of dementia. These behaviors often include repetitiveness, delusions (false beliefs), hallucinations, agitation, aggression, altered sleeping patterns, wandering, hoarding and resisting care (Lewis et al., 2017). Often, behaviors will be unpredictable and will challenge care-givers. It is vital to remember that these behaviors are not intentional and are often a patient’s way of responding to pain, frustration, temperature extremes and anxiety (Lewis et al., 2017). Regularly monitor patients’ comfort and anticipate their needs.

Care Considerations

- Check the patient for changes in vital signs.
- Assess urinary or bowel problems.
- Assess pain.
- Check the environment for irritants such as extremes in temperature or excessive noise.
- Redirect the patient; use distraction and reassurance.
- Repetitive activities, music, massage, aromas or favorite objects may be soothing to the patient.
- Avoid being confrontational.
- When a patient is asking for something or someone, acknowledge requests. For example, if a patient is saying “I want my mom!”, respond with “You really miss your mom; she helps you with a lot of things.” Then try to determine what the person is needing that mom represents. (Lewis et al., 2017)

Aggression

Aggressive behaviors may be verbal (shouting, name calling) or physical (hitting, pushing). Aggression can happen suddenly, with no apparent reason, or can result from a frustrating situation. Try to understand what is causing the person to become angry or upset (Alzheimer's Association, 2012).

Care Considerations

- Try to identify the immediate cause of aggressive behavior.
- Rule out pain as a source of stress.
- Focus on feelings, not facts.
- Don't get upset; be positive and reassuring.
- Limit distractions.
- Try a relaxing activity (music, massage or exercise).
- Shift focus to another activity.
- Approach the patient from the front.
- Explain what you are about to do and give the patient time to process before initiating any task/activity, especially related to personal cares.

(Alzheimer's Association, 2012)

Anxiety or Agitation

A person with dementia may feel anxious or agitated. They may become restless and need to move around or pace. The person may become upset in certain places or focus on specific details, such as what they had for lunch where their family is or the location of a misplaced item. (Alzheimer's Association, 2012).

Care Considerations

- Listen to the frustration to find out what may be causing the anxiety.
- Provide reassurance with calming phrases.
- Involve the person in activities (such as art or music).
- Modify the environment: Decrease noise and distractions or relocate.
- Reduce choices, as choosing between multiple options may increase anxiety.
- Find outlets for energy, as they may be looking for something to do.
- Start activities that allow the patient to assume aspects of past, familiar roles (such as a doll for a former daycare employee or pet therapy with a patient who used to own dogs.)

(Alzheimer's Association, 2012)

Repetition

A person with dementia may do something over and over again, such as repeating a word, question or activity. Repetition may offer them comfort, security and familiarity. They may also pace or undo what has just been done. These actions are rarely harmful to the person with dementia but can be stressful for the caregiver (Alzheimer’s Association, 2012). If a patient is dwelling and repeating a positive reminiscence, it is best to allow the patient to continue. Reminiscing is beneficial for their brain, even if it is annoying for caregivers.

Care Considerations

- Look for a reason behind the repetition—a specific cause or trigger.
- Focus on the emotion, not the behavior.
- Turn the action or behavior into an activity.
- Provide an answer that they may be looking for.
- Use memory aids and offer reminders that are useful to the individual, such as notes, clocks, calendars or photos.

(Alzheimer’s Association, 2012)

Suspicion

Memory loss and confusion may cause a person with dementia to perceive things in new, unusual ways. They may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes a person may misinterpret what he or she sees and hears. A potential side effect of person-centered approach/history-taking is that talking about something from the patient’s past may cause them to be concerned that people are “talking about them.” A better approach would be to ask yes/no questions around a known fact and let them lead a conversation or say, “Tell me more.”

Care Considerations

- Don’t take offense; try to understand what the person perceives as reality.
- Don’t argue or try to convince.
- Offer a simple answer.
- Switch the focus to another activity.
- Duplicate any lost items.

(Alzheimer’s Association, 2012)

Medication Considerations

- Avoid anticholinergics in fronto-temporal dementia.
- Avoid antipsychotics in Lewy Body, Parkinson’s and progressive supranuclear dementia.
- Selective serotonin reuptake inhibitors (SSRIs) are generally advised for all dementias.
- Avoid using benzodiazepines in all dementias. (Braus, A., 2019)
- Benzodiazepines decrease inhibitions in late-stage dementia. (Robbins, K., 2019)
- Evaluate for anxiety and delirium first, then treat dementia.
- Depression: Start with citalopram or sertraline.
- Psychosis with distressing symptoms: Start with quetiapine, olanzapine or risperidone.
- Insomnia: Consider mirtazapine or trazodone.
- Some medications may cause increased confusion.

Partner with Agrace pharmacist and physician, as there are many factors that can affect medications and patients.

Clinical Education Resources

- [Agrace Eligibility Guide by Diagnosis](#)
- Alzheimer’s & Dementia Alliance Handouts
 - Structuring the Daily Routine
 - Creating Enjoyable Involvement
 - Ways to make Connections
 - Activities Ideas: To Add Meaning & Pleasure to Daily Living for Individuals with Dementia
- Alzheimer’s Association packets
 - Dementia Care Practice Recommendations for Assisted Living Residences & Nursing Homes
 - Dementia Care Practice Recommendations for Assisted Living Residences & Nursing Homes: Phase 3 End-of Life Care
 - Dementia Care Practice Recommendations for Professionals Working in a Home Setting
- Alzheimer’s Society: “This is Me” worksheet
- Agrace protocols (accessed through Inside Agrace)
 - [Pain assessment protocol](#)
 - [Pain assessment in advance dementia \(PAINAD\) scale](#)

- [Delirium symptom management](#)
- [Wound care management protocol](#)
- Fall assessment and prevention protocols:
 - [HomeCare protocol](#)
 - [Inpatient Unit protocol](#)
- Agrace resource: Teepa Snow webinar “Dementia and De-escalation”
- Surviving Alzheimer’s – Paula Spencer Scott

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