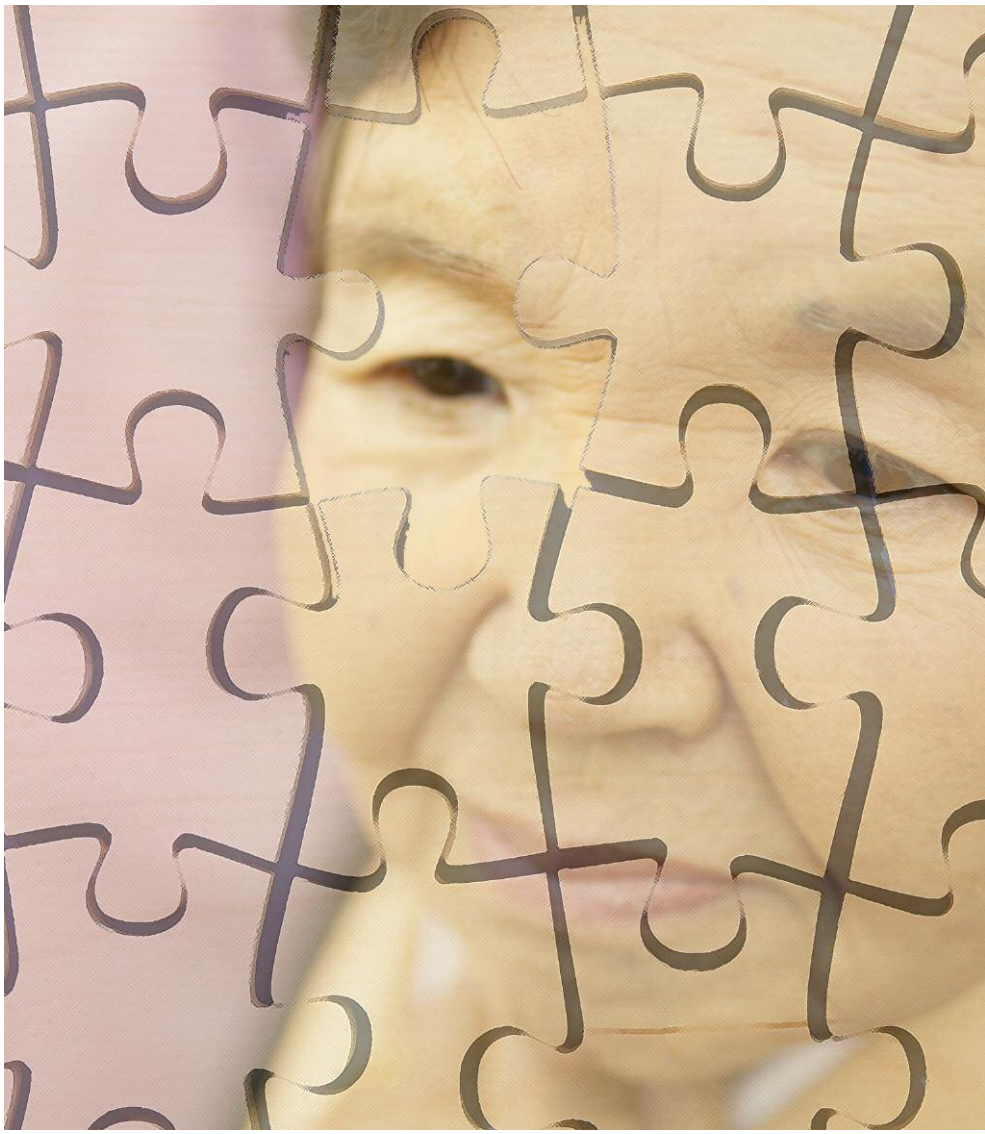
AMDA Clinical Practice Guideline: Dementia in Assisted Living

Dementia is a common condition in assisted living facilities. According to the Alzheimer's Association, half or more of elderly ALF residents have Alzheimer's disease or other dementia. One study, the National Survey of Assisted Living Facilities, concluded that about one-third of elderly residents have moderate to severe cognitive impairment indicative of dementia.

Nonetheless, statistics on prevalence vary, partly because of the differences in the way dementias are recognized in this population. In fact, many AL residents with dementia do not have a formal diagnosis of the condition, and staff often don't recognize individuals as having Alzheimer's disease or other dementia—particularly when the condition is in the early stage.

This adaptation of the American Medical Directors Association's (AMDA) clinical practice guideline on dementia in long term care addresses the recognition, assessment, treatment, and monitoring of this condition in the assisted living setting.



Definition

Dementia is a syndrome (a collection of signs and symptoms) characterized by progressive decline in multiple areas of cognitive function,

Table 1.
Diagnoses That Suggest the Presence of Dementia

- Alzheimer's disease
- Drug, alcohol, or anoxic encephalopathy or dementia
- Huntington's disease
- Lewy body disease
- Multi-infarct (vascular) dementia
- Normal-pressure hydrocephalus
- Organic brain syndrome
- Parkinson's disease
- Pick's disease
- Progressive supranuclear palsy
- Pseudodementia
- Senile memory loss

which eventually produces significant deficits in self-care and social and occupational performance. The following are related key terms:

- Cognition: activities related to organizing memory, sensation, and thinking
- Behavior: an individual's observable actions
- Mental status: an individual's overall level of alertness, activation, and responsiveness to the outside world

Recognition

Step 1. Does the resident have a history of dementia? Review available information about the individual's recent past physical, functional, cognitive, and behavioral status. Look for previous diagnoses that may indicate the presence of dementia (Table 1). Check medication regimens/orders for medications that can alter cognitive function (eg, psychotropics, sedatives, hypnotics, cardiac antiarrhythmics, and medications with significant anticholinergic properties).

If the resident recently has been treated for an acute medical or psychiatric illness, carefully review all available transfer information, including recent hospital discharge summaries. Also review other pertinent information, including information obtained from speaking with the resident, family, and/or caregivers.

Search for evidence of specific impairments or symptoms (eg, neurological or behavior symptoms) that may suggest underlying dementia (Table 2). Abnormal cognition and problematic behavioral symptoms do not necessarily imply dementia; they may indicate the presence of other conditions or impairments such as delirium, depression, hypothyroidism, subdural hematoma, normal-pressure hydrocephalus, or vitamin B12 deficiency.

Step 2. Does the resident have current signs or symptoms of dementia? Nurses, caregivers, practitioners, and others should observe the resident's current physical, functional, and psychosocial status. Function may be assessed using one of several instruments, such as the Functional Activities Questionnaire. Cognition may be assessed using the Mini-Mental State Examination (MMSE), the Clock Drawing test, Blessed Orientation-Memory-Concentration Test, or other comparable instruments.

Dementia typically is a chronic condition, with gradual progression of symptoms such as memory loss, inability to follow directions, and inability to recognize familiar objects or use them correctly. Residents with dementia may display worse symptoms at different times (eg, at night). However, unlike people with delirium, they usually do not have altered levels of consciousness or significant day-to-day fluctuations in their function or thinking.

Residents with dementia tend to have fewer somatic symptoms (eg, headaches, gastrointestinal distress, musculoskeletal pain) than those with depression. In addition, individuals with dementia tend to perform poorly on tasks involving automatic processing (eg, writing their name or eating meals).

Recent, abrupt changes in function, level of consciousness, and behaviors in residents with dementia almost always result from other acute conditions. For example, a resident may have both alcohol-related dementia and delirium or both Alzheimer's disease and a decline precipitated by recent pneumonia.

Findings should be documented as appropriate and communicated to the resident's physician or other clinician.

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Table 2.
Neurological Impairments or Behaviors That May Suggest Underlying Dementia

Problem	Behavioral Consequences	How Caregivers May Misinterpret These Disease Manifestations
Amnesia (loss of memory)	Repeats questions often, misplaces objects	"Frustrating" "Paranoid"
Apraxia (loss of ability to coordinate learned movements)	Cannot use utensils, dress, use toilet unassisted	"Won't eat" "Uncooperative" "Incontinent"
Aphasia (inability to speak or understand)	Cannot follow directions or engage in conversation	"Uncooperative" "Withdrawn"
Agnosia (inability to recognize what is seen)	Cannot recognize faces, familiar places, or objects	"Frightened, combative" "Wandering" "Stealing others' belongings"

Source: Alzheimer's Association. *Key Elements of Dementia Care.* 1997. Chicago, IL.

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Consider if the resident is at risk for the onset of progression of dementia. Certain conditions may predispose patients to dementia. These include:

- Alcohol abuse
- Brain tumors
- Cerebrovascular disease
- Chronic subdural hematoma
- Heavy metal exposure
- HIV infection
- Hypothyroidism (untreated)
- Lyme disease
- Neurosyphilis
- Parkinson's disease
- Pick's disease
- Vitamin B12 deficiency

At the same time, it will be helpful to identify patients who are at risk for progression of dementia as a result of acute conditions or medication use. The practitioner should identify and manage residents with these risk factors promptly (Table 3).

Table 3.
Risk Factors for Exacerbation of Dementia-Related Symptoms

Host-Related Factors
- Infections
- Significant pain or trauma
- Urinary retention
- Nutritional deficiencies (including vitamin B12 deficiency)
- Stroke or seizure
- Myocardial infarction
- Dehydration
- New or unstable arrhythmias
- Depression
- Hypo- or hyperthyroidism

Iatrogenic or Nosocomial Factors
- Drug toxicity or adverse drug reactions
- Recent admission to the facility
- Recent hospitalization
- Transfer to a new environment
- Recent surgery under general anesthesia

Assessment

Step 3. Determine if further work-up is useful and appropriate. The practitioner must decide if a work-up is likely to be medically useful—that is, whether testing and examination is likely to better define the resident's status or the cause of his or her symptoms or impairments and help to guide management.

If necessary, the practitioner then should consult with the resident (to the extent feasible), the resident's family, and other interdisciplinary team members to determine if a work-up is appropriate—that is, whether the information gained is likely to result in or change interventions that may improve the resident's quality of life.

The primary aim of a diagnostic work-up in residents with dementia is the identification of potentially treatable conditions. All or part of this work-up may not be indicated if the resident has a terminal or end-stage condition, if it would not change the resident's management, if the resident or surrogate decision-maker has refused treatment, or if the burden of the work-up is greater than the benefit of treatment.

A medical assessment serves several important purposes. It identifies the links between particular medical conditions and the resident's functional impairments and disabilities to enable a more targeted management approach.

Step 4. Verify that the resident meets the criteria for a diagnosis of dementia. Residents most likely to have dementia manifest impaired mental status and function. If the resident meets the criteria for a diagnosis of dementia (Table 4), proceed through the subsequent steps in this document. If the diagnosis of dementia is not made or confirmed, or if a resident with a prior diagnosis of dementia has a recent significant condition change, consider other causes of the resident's symptoms before concluding either that the resident has dementia or that recent changes are due to dementia.

Step 5. Identify the cause(s) of dementia. Dementia also has a cause, most commonly Alzheimer's disease or vascular disease. However, a specific cause is not readily detectible in all cases. Determining the cause may help to prevent further deterioration or may establish a prognosis.

In some residents, dementia may be so far advanced or function so impaired that additional diagnostic criteria is not likely to be useful.

A neurological, psychological, or psychiatric assessment may help to

Table 4.
Diagnostic Criteria for Dementia

A. The development of multiple cognitive deficits manifested by both
   (1) Memory impairment (impaired ability to learn new information or to recall previously learned information)
   (2) One or more of the following cognitive disturbances:
      a) Aphasia (language disturbance)
      b) Apraxia (impaired ability to carry out motor activities despite intact motor function)
      c) Agnosia (failure to recognize or identify objects despite intact sensory function)
      d) Disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A(1) and A(2) each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning

Adapted from DSM-IV. American Psychiatric Association. *Diagnostic and Statistical Manual of Psychiatric Disorders*, 4th ed. 1994. Washington DC: Brandon/Hill.

guide additional evaluation. Some tests may reveal the presence of a tumor, bleed, or other structural abnormalities. However, these may not correspond to functional or cognitive impairments. Conversely, functional and cognitive impairments may exist despite unremarkable test results.

Step 6. Identify the resident's strengths and deficits. Soon after admission or a significant condition change, assess the resident's capabilities in various domains, including medical, functional, emotional, social, cognitive, and behavioral.

It is challenging to quantify mood, cognition, and behavior. Different observers may describe or rate the same situation very differently. To ensure objectivity and accuracy as far as possible, choose and consistently use standardized terminology and appropriate evaluation tools.

Mood alterations may be characterized by their onset, duration, and severity. Describe cognition by its specific aspects, such as short-term memory and immediate recall. Behavior may be described by specific characteristics to maximize objectivity and consistency.

No matter what else has been identified as a cause of problematic behavior or altered mental state, it always is important to review the resident's medications for any drugs that may cause or contribute to impaired consciousness, increasing confusion, and problematic behaviors.

Step 7. Define the significance of the resident's symptoms, impairments, and deficits. Residents with dementia often have impairments in multiple domains. These impairments may affect function and quality of life as much as the resident's cognitive and behavioral deficits do. Many of these deficits also may be problematic for the resident's family and caregivers. For this reason, they should be addressed promptly.

Define as accurately and fully as possible the nature, scope, and severity of the resident's behaviors and cognitive and functional impairments. Before addressing management, determine the significance of the symptoms or impairments to the resident.

Traditionally, socially unacceptable behaviors in residents with dementia have been treated with medications. This approach largely has yielded to the view that many behaviors are consistent with the resident's stage of dementia and previous history and should be anticipated and accommodated rather than seen as a symptom to be treated. Behaviors generally regarded as socially unacceptable may be tolerable because they are expected manifestations of the disease or are inconsequential to the resident or others.

No matter what else has been identified as a cause of problematic behavior or altered mental state, it always is important to review the resident's medications for any drugs that may cause or contribute to problematic behaviors.

For example, a resident may display anxiety, wander, or make repetitious comments that may be perceived by others as annoying. Although such behaviors may not be preventable, they may be managed through basic behavioral techniques or environmental changes. In some cases, the most appropriate strategy may be to work with the resident's caregivers or family members to help them understand and accept the behaviors.

However, an impairment may become disruptive or dangerous to the resident's function or may cause the resident considerable distress. Moreover, an impairment to the resident may have excessively disruptive or dangerous effect on family members or caregivers or may infringe on other residents' rights or on the ability of staff to care for other residents. Such situations may require more aggressive management, including the use of medications.

Step 8. Identify triggers for disruptive behavior. Behavioral symptoms in dementia residents often are triggered or exacerbated by physical, organizational, or psychosocial factors. Identifying these triggers enables the use of targeted interventions to prevent or manage the disruptive behavior.

Examples of factors that may be relevant to disruptive behaviors include:

- What was the resident doing when the behavior occurred?
- What made the resident's behavior better or worse?
- What was happening just before the behavior occurred?
- Was there a change in the environment just before the behavior occurred?
- Who was near the individual at the time of the incident?
- What was the impact of the behavior on other people?
- Did a specific circumstance cause recurrence of the behavior?

Treatment

Step 9. Prepare an interdisciplinary care plan. Ensure that all parts of the care plan are consistent and based on appropriate resident assessment.

Step 10. Optimize function and quality of life and capitalize on remaining strengths. Residents with dementia often benefit from efforts to optimize their function and quality of life. Such efforts often include activities that target cognitive function (eg, solving puzzles or engaging in arts and crafts), physical function (eg, exercising, playing

games), and spiritual well-being (eg, attending religious services).

Consider using complementary and alternative therapies. These therapies may help to optimize function and quality of life in residents with dementia. For example, sensory stimulation may help to preserve meaningful contact with the outside world. Arts, crafts, and peg-board activities may be appropriate for some residents.

Prevent excess disability. A resident may display a greater degree of functional deficit than is warranted by his or her impairment. Such disability may result from unrecognized or inadequately treated medical conditions; adverse medication effects; or emotional, psychological, and environmental factors. Addressing these factors may improve the resident's function. For example, a resident who is physically aggressive may calm down if noise in his or her environment is reduced. A resident who is lethargic may be more active if medications causing drowsiness are reduced or discontinued.

Consider medical interventions if appropriate. Residents with dementia related to specific causes may benefit from certain medical interventions. For example, interventions such as the use of anticoagulants, antihypertensive agents, and lipid-lowering or antiplatelet agents may prevent worsening of symptoms in a resident with multi-infarct dementia.

Cholinesterase inhibitors may reduce the rate of decline in cognitive function and may improve behavioral symptoms in residents with mild to moderate dementia. Three agents in this class—donepezil, rivastigmine, and galantamine) are currently approved by the U.S. Food and Drug Administration (FDA) to treat individuals with dementia of the Alzheimer's type.

Consider the use of a cholinesterase inhibitor with residents who have a diagnosis of dementia who have mild to moderate cognitive and functional decline that is not caused by an underlying treatable condition and in whom drug therapy is not clinically contraindicated.

Table 5.
Environmental Aspects that Can Be Assessed and Adapted to Optimize Quality of Life for Residents with Dementia

- Personalize the environment to provide a more home-like atmosphere
- Minimize noise
- Provide adequate lighting
- Provide a variety of daily activities (physical, spiritual, and cognitive)
- Provide family support and education
- Provide comfortable seating and mobility devices
- Provide way-finding cues
- Provide relevant staff education and training
- Provide space for both privacy and socialization
- Provide a safe and secure environment for residents

Before initiating drug therapy, it is important to ensure that the resident is appropriately assessed. When medications are used, it is important to be familiar with the drug's side effect profile.

Memantine hydrochloride is the only medication currently approved by the FDA to treat patients with moderate to severe dementia of the Alzheimer's type. Other agents, including selegiline, nonsteroidal anti-inflammatory drugs, estrogen, and vitamin E, have been tried in the treatment of dementia. However, strong evidence is not available to support their use; and some of these may be associated with adverse effects.

Behavioral symptoms may be related to an acute medical condition and may respond to appropriately selected medications. Primary medical intervention for behavioral symptoms may be appropriate in certain circumstances, such as when violent behavior doesn't respond to other interventions or when the resident has distressing hallucinations, delusions, or paranoid ideation. In such situations, however, medications should be supplemented or replaced by non-pharmacological approaches (see Table 5) if feasible and as soon as the resident's condition allows.

Before initiating drug therapy, it is important to ensure that the resident is appropriately assessed. This involves discussing the goals of therapy with the resident and his or her family and setting realistic expectations based on the resident's condition and an understanding of the likely benefits and limitations of current drug therapy for dementia. When medications are used, it is important to be familiar with the drug's side effect profile.

It is important to monitor residents closely for adverse drug reactions and to obtain pertinent laboratory tests.

Step 11. Address socially unacceptable or disruptive behaviors. The management of socially unacceptable or disruptive behavior should

Table 6.
Evaluation of Disruptive or Socially Unacceptable Behavior

1. Describe the behavior in detail.

- To discern the pattern of the behavior, describe what occurs, when it occurs, how often it occurs, and who else tends to be involved in the situation. Be very specific and use objective language (e.g., "Mrs. S struck caregiver's shoulder with open hand when the caregiver was leaning over to tie Mrs. S's shoe," rather than "Mrs. S was combative during care").
- Describe the conditions in which the behavior occurred. Identify what preceded it and what happened as a result of the behavior.
- Document the occurrence of the behavior and the conditions in which it occurs for a period of time (e.g., 2 weeks) to establish a baseline.

2. Examine the extent to which the behavior is a problem.

- Identify who is raising concern about the behavior (family member, caregiving staff, the patient with dementia, or other residents of the facility).
- Who experiences the behavior as a problem? Is anyone placed in physical or other danger by the behavior?
- Can the problem be solved by reducing others' exposure to the behavior or changing others' tolerance of the behavior (e.g., by altering staff perceptions and tolerance for sexual invitations or swearing) rather than changing the behavior itself?

3. Try to determine why the patient is engaging in the behavior.

- To what extent can the behavior be explained by understanding the way the patient with cognitive deficits experiences and reacts to the situation? For example, does hitting or screaming during undressing occur because the resident feels threatened?
- Did something in the environment trigger the behavior? For example, is there too much, too little, or inappropriate stimulation? Has a change occurred in the environment?
- Did something or someone in an interaction between the patient and another person trigger the behavior? For example, did the caregiver approach the patient on his or her impaired side or did the caregiver move too fast?
- Is the task too difficult? Are there too many task steps to keep in order?
- Has something relating to the patient's preferences, habits, or expectations changed? For example, is the patient accustomed to eating breakfast before taking a bath? To what extent is the resident's health or emotional status playing a role in the problematic behavior?

4. Describe the interventions attempted to date and document whether they have been successful or not. Describe the conditions under which interventions are more likely to be effective.

Source: Alzheimer's Association. *Key Elements of Dementia Care*. 1997. Chicago, IL.

be based on a careful evaluation and description of the behavior (see Table 6). It is important to define the target symptom (eg, self-injury or severe agitation related to delusions) to be addressed and identify care goals. Generally, unless the behavior potentially endangers the resident or others, nonpharmacological interventions should be considered first while efforts are made to identify the causes of the problem.

Some dementia-related behaviors that result in injury may be preventable. For example, residents with dementia who feel threatened may exhibit aggressive behaviors. Staff may reduce or limit these reactions by altering approaches to activities such as bathing or altering the resident's environment to suit specific needs or concerns.

Behavioral outbursts also may be due to "catastrophic reactions," sudden emotions the resident exhibits when he or she feels frightened, confused, or overwhelmed. These behaviors tend to occur suddenly and resolve quickly when the source of distress is removed or the resident's attention is diverted. Acute changes in behavior or cognition in residents with dementia also may present delirium.

Table 7 lists medication options used to manage behavioral and psychological symptoms in residents with dementia. They should be utilized only after careful consideration of the causes of symptoms and only when a clear indication is present and nonpharmacological strategies or other treatments are not pertinent or have associated risks. Their effects should be monitored regularly—especially when the resident has other risk factors or also is taking other medications affecting the cardiovascular or central nervous system.

Step 12. Manage functional deficits. Residents with dementia invariably have functional deficits. Caregivers need to be aware of these deficits and should be trained to help the resident compensate for them while helping to maximize unimpaired function. Focus should be on maintaining the resident's dignity and encouraging him or her to use whatever capacities remain. It will be important to train staff to help residents with activities of daily living without provoking negative reactions.

A restorative nursing program may help to optimize the function of a resident who has impaired cognition and behavior. This may include the use of specific techniques such as prompted voiding for incontinent residents, the use of specialized utensils to assist with eating, and environmental modifications to optimize safe mobility.

Step 13. Address pertinent psychosocial and family issues. Pertinent issues may include personal and family relationships and other family issues. Facilitate appropriate activities and interpersonal relationships

Table 7.
Medication Options Commonly Used To Manage Behavioral and Psychological Symptoms In Patients With Dementia

Drug	Route of Administration
Haloperidol	Oral, IM,
Risperidone	Oral
Olanzapine	Oral, IM
Quetiapine	Oral
Ziprasidone	Oral, IM
Aripiprazole	Oral
Trazodone	Oral
Carbamazepine	Oral
Divalproex sodium	Oral

IM: intramuscular, IV: intravenous
Source: Smith AG. Behavioral problems in dementia: Strategies for pharmacologic and nonpharmacologic management. *Postgrad Med* 2004; 115(6): 47-56.

among residents with dementia. Work closely with families to help them understand the resident's situation and the plans for optimizing his or her function. Impaired cognition and socially unacceptable or disruptive behavior often are frightening and confusing to family members, who may not understand the causes and significance of these symptoms. They may overestimate the benefits of certain interventions, such as physical restraints, or may be unaware of their risks. Conversely, families may resist some beneficial interventions that they mistakenly believe are dangerous, such as the use of psychoactive medications in situations when these are likely to be helpful. It may be useful to explain to family members how impairments are defined, causes identified, and management options chosen.

Step 14. Address ethical issues. These include:

- Defining decision-making capacity and identifying situations that require substitute decision-making
- Addressing situations related to everyday life (eg, resident preference, boundaries on sexual expression and socially acceptable behaviors)
- Discussing possible limitations on medical interventions such as hospitalization, resuscitation, and artificial nutrition and hydration (tube feeding)

It may be useful to explain to family members how impairments are defined, causes identified, and managment options chosen.

Step 15. Manage risks and complications related to dementia, other conditions, or treatments. Residents with dementia often have complications directly related to their disease (eg, impaired mobility, urinary incontinence). They also may be at risk for indirect complications such as falls, adverse medication reactions, and aspiration related to tube feeding.

Caregivers and practitioners should anticipate these significant risks and complications and be prepared to address them when they occur. Such plans should address not only medical management but also ethical issues.

The onset or worsening of medical illnesses or other problems in residents with dementia often precipitates a series of events, including hospitalizations, function decline, and altered nutritional status, that affect many aspects of the resident's life and care. Understanding these risks and promptly addressing problems sometimes can prevent hospitalizations and their related risks.

Monitoring

Step 16. Monitor the resident's condition and adjust management as appropriate. Monitor the resident's progress periodically, using the same methods and criteria used in the initial assessment.

Generally, dementia either will stabilize or progress. Progression may be gradual or rapid. Following an acute condition change, the resident may return partially or completely to his or her baseline state or may decline further.

If the resident's condition remains stable, continue pertinent interventions. If he or she declines rapidly or progressively, the practitioner, other direct care providers, and possibly a consulting psychiatrist should assess the resident for possible reasons for the decline.

Periodic attempts to taper one or more psychoactive medications sometimes are warranted, unless the nature of the condition (eg, psychotic delusions) or past experience suggests that doing so may result in a return or an exacerbation of the resident's symptoms. Medication reduction efforts should follow published recommendations. ALC

To order the AMDA CPG on dementia or other AMDA clinical practice guidelines, go the organization's Web site at www.amda.com.