

Review Article

Ongoing Medical Management to Maximize Health and Well-being for Persons Living With Dementia

Mary Guerriero Austrom, PhD,^{1,2,3,*} Malaz Boustani, MD, MPH,^{4,5} and Michael A. LaMantia, MD, MPH^{6,7}

¹Department of Psychiatry, ²Indiana Alzheimer Disease Center, ³Office of Diversity Affairs, and ⁴Department of Medicine, Indiana University School of Medicine, Indianapolis. ⁵Regenstrief Institute Inc., Indiana University School of Medicine, Indianapolis. ⁶Division of General Internal Medicine and Geriatrics, University of Vermont, Burlington. ⁷University of Vermont Center on Aging, Burlington.

*Address correspondence to: Mary Guerriero Austrom, PhD, Department of Psychiatry, 355 W 16th Street, Suite 2800, Indiana University School of Medicine, Indianapolis, IN 42602. E-mail: maustrom@iupui.edu

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Abstract

Background and Objectives: Persons living with dementia have complex care needs including memory loss that should be taken into account by providers and family caregivers involved with their care. The prevalence of comorbid conditions in people with dementia is high and, thus, how primary care, community providers and family caregivers provide best practice care, person-centered care is important.

Research Design and Methods: Care providers should understand the ongoing medical management needs of persons living with dementia in order to maximize their quality of life, proactively plan for their anticipated needs, and be as well prepared as possible for health crises that may occur.

Results: This article provides eight practice recommendations intended to promote understanding and support of the role of nonphysician care providers in educating family caregivers about ongoing medical management to improve the wellbeing of persons living with dementia.

Discussion and Implications: Key among these are recommendations to use nonpharmacological interventions to manage behavioral and psychological symptoms of dementia as the first line of treatment and recommendations on how to best support the use and discontinuation of pharmacological interventions as necessary.

Keywords: Caregiving-formal, Dementia, Evidence-based practice, Person-centered care

In this article, we address the ongoing medical care that most people living with dementia need over the course of the disease. Persons living with dementia have complex care needs including memory loss, for example, that may impede their ability to take medicines on a regular basis or communication difficulties that make it more difficult for them to report symptoms that they may be experiencing (Bunn et al., 2014). Persons living with dementia can have many of the same comorbid conditions that persons

without dementia have, but frequently have more encounters with acute care providers, including doctors and nurses at hospitals and emergency departments. A recent systematic literature review by Bunn and colleagues (2014) suggests that significant numbers of people with dementia have a comorbid health condition, such as diabetes, visual impairment, or stroke. Because this was a large review of over 65 studies, prevalence numbers varied, however, as Bunn and colleagues (2014) report the prevalence of type

2 diabetes ranged from 6% to 39% in people with dementia; similarly 3% of hospitalized older adults in the United Kingdom to 34% of community dwelling older adults in a U.S. sample had a history of stroke and dementia. Two studies reported the prevalence of dementia in people with visual impairment recruited via eye clinics. In one 19% of people with macular disease had dementia and in the other 20% of people with glaucoma had memory impairment and 22% impaired executive functioning.

There may be a variety of factors that contribute to this finding. For example, people with dementia may be less likely to attend regular appointments or to notice or report relevant symptoms and they may be more reliant on caregivers to manage and facilitate appointments. It is also possible that clinicians may be more reluctant to investigate and treat individuals with dementia either because of the difficulties involved in securing cooperation or because treatments are considered inappropriate for older patients with multiple comorbidities. In addition, if dementia is symptomatic, then the dementia can become clinically dominant and detract from the management of other conditions like diabetes mellitus (Bunn et al., 2014). It is useful for nonphysician care providers to understand how care ideally should be provided to persons with dementia in order to maximize their quality of life, proactively plan for their anticipated needs, and be as well prepared as possible for health crises that may occur.

As reviewed earlier in this special issue, the number of persons affected by Alzheimer's disease and other dementias is projected to increase over the coming decades. With these increases, we can expect to see a greater demand for services for persons living with dementia across all health care settings, though it might be expected that this demand will be greatest in those venues that most commonly provide care to persons living with dementia today. Some of these settings, such as memory care centers and long-term care centers including nursing homes, have long-standing experience in providing care to large numbers of persons living with dementia; whereas in other settings, including primary care offices, medical specialists' offices, hospitals, and emergency departments, more preparation will be needed to address the unique care needs of persons living with dementia as their numbers increase.

For clarity, this article uses the terms, physician, medical care provider, primary care provider, and acute care provider, to refer to physicians and medical care providers including nurse practitioners and physician assistants who work in primary care offices, medical specialist offices, hospitals, and emergency departments. It uses the terms, family, family members, and caregivers to refer to relatives, friends, and neighbors who provide care for a person living with dementia. Lastly, it uses the terms, nonphysician care provider and community or residential care provider, to refer to individuals who work in area agencies on aging, aging and disability resource centers, information and referral agencies, senior centers, senior housing, personal care homes, assisted living facilities, nursing homes, home

health agencies, homemaker and personal care agencies, care management agencies, adult day centers, pharmacies, and public health and community nursing agencies. Examples might include pharmacists; social workers, physical, occupational, and speech therapists. Nonphysician care providers also include self-employed geriatric care consultants, family counsellors, and home care aides.

Understanding Common Comorbidities

It is important for nonphysician care providers who work in community and residential care settings to remember that persons living with dementia have medical care needs in addition to care needs related to the dementia. Typically, medical care for the person living with dementia is provided by a family medicine physician or internist, who often works with a neurologist or psychiatrist depending on the person's needs. Persons living with dementia may see several doctors, therefore, having a consistent relationship with a primary care provider can help coordinate care and potentially prevent unnecessary hospitalizations. Family caregivers should expect that physicians and medical care providers across all health care settings should provide care to persons living with dementia in a manner that respects their personhood, takes into account the variable ability of individuals living with dementia to participate in or direct their health care, and reflects the high likelihood concerned family members should be involved and included in any medical decision making. Like other older adults, persons living with dementia commonly suffer from high blood pressure, heart disease, diabetes, as well as other conditions that become more common with age. Care for these common conditions should not be provided in isolation from the person's dementia but rather take the person's dementia into account (Bunn et al., 2014; Schubert et al., 2006).

Medical issues can worsen cognition, and many people living with dementia have other conditions that can and do impact cognition. Unfortunately, it can be difficult to recognize when the person living with dementia is ill. Persons living with dementia are known to be less likely to report symptoms or by the time they are asked about them, the symptoms have passed, and they can't give an accurate report. Often, the only symptom one can see is the worsening of confusion or behaviors, which makes it very difficult to know if this is due to the progression of the underlying dementia or if there is a new problem to be addressed. When there is a significant and sudden change in cognition and behavior, it is important that the person with dementia, their caregiver and involved nonphysician care providers report this to the person's primary care provider quickly.

In order to assure that persons living with dementia and their caregivers receive medical care and other services that are consistent with their goals of care, they need to be first offered an explanation of the condition, its prognosis, and potential treatment options, including pharmacologic and nonpharmacologic approaches. Evidence to date suggests

that only a minority of persons living with dementia are recognized as having the condition by their primary care providers and that their caregivers experience increased levels of stress, depression, and mortality (Boustani, Sachs, & Callahan, 2007; Fowler, 2012; McKhann et al., 2011). There are evidence-based programs that support the process of identifying and diagnosing persons with dementia, provide on-going support to them and their caregivers, and help address their on-going and evolving biopsychosocial needs (Callahan et al., 2014; LaMantia et al., 2015; Tan, Jennings, & Ruben, 2014). Speaking with persons living with dementia and their caregivers about the diagnosis of dementia should not be done in a hurried manner, but rather should be approached with sensitivity and in a manner that recognizes the particular needs of each individual (Wilkinson & Milne, 2003). Further, speaking with persons living with dementia and their caregivers about the diagnosis and its prognosis does not need to be done in an overly negative manner that removes hope. Instead, an approach that acknowledges and incorporates the many advances that have been made in addressing the medical and social needs of the person living with dementia and their caregivers is recommended.

Persons living with dementia and their family members often fear that after the diagnosis, their physician will abandon them because there are currently no disease modifying treatments available (Boustani et al., 2011; Fowler et al., 2012). Physicians and other medical care providers can offer important education and psychosocial support to both the person with dementia and the family caregiver (Austrom & Lu, 2009; Callahan et al., 2011; McKhann et al., 2011). Medical care providers also have a unique opportunity to educate the person living with dementia and their family members about what to expect over the course of disease. Indeed, the needs of persons with dementia can be expected to change over time. Early on, medical providers, nonphysician care providers, and caregivers may need to provide little additional support than that which is given to persons without dementia, however with time the amount of support should be titrated gradually in a personalized manner that responds to the individual's unique pattern of increasing need and respects his or her autonomy (Callahan, 2017). Medical providers can, additionally, provide referrals to available support services and can monitor judgment and safety issues so that the person living with dementia can remain independent and community-dwelling for as long as possible (Boustani et al., 2011; Callahan et al., 2012; Farran et al., 2007; Schulz et al., 2003). Nonphysician care providers can play an instrumental role in supporting person living with dementia and their care partners after they have been diagnosed by their physician.

Addressing Behavioral and Psychological Symptoms of Dementia

One of the more common complications that can arise in the care of persons living with dementia is the development

of behavioral disturbances. Such symptoms are thought to occur in between 75% and 98% of community dwelling individuals and can become more common as the dementia progresses. Symptoms can include agitation, wandering, resistance to care, combativeness, nighttime arousals that interfere with sleep and caregivers' sleep, and psychotic symptoms (Ballard & Waite, 2006; Fung et al., 2012; Sink, Covinsky, Newcomer, & Yaffe, 2004; Teri et al., 2000). It is important that families and nonphysician care providers bring these symptoms to the physician's attention so that the symptoms may be evaluated thoroughly and a plan for their management developed.

In evaluating the person's behavioral disturbance, it is important that the context in which the behavior occurs is considered. This information is most often obtained from family members or a nonphysician care provider. These individuals may be most able to describe whether this is a continuation of an old behavior that should come to medical attention for some other unrelated reason or describe accurately if this is a new or worsening symptom. A useful framework for physicians in making an evaluation of a new symptom is that initially developed by Sharon Inouye (Inouye, 1999; Inouye & Charpentier, 1996) to describe delirium. This framework consists of predisposing factors inherent to the individual which set the stage upon which precipitating factors then cause the concerning behavior to occur. In this model, examples of predisposing factors could include the stage of the person's dementia, the presence of chronic comorbid illnesses like congestive heart failure or chronic obstructive pulmonary disease, and sensory impairments like decreased hearing ability or decreased vision caused by cataracts, glaucoma, or macular degeneration for example. Precipitating factors might include the use of sedating or stimulating medications, the presence of untreated pain, exposure to frightening or disturbing stimuli, the inability of the individual to get adequate rest, the removal of the person from his or her usual environment or normal routine, and the development of delirium (Inouye, 1999).

In a recent study by Kerns and colleagues (2017), family caregivers and nurses of persons with dementia living in the community and in residential care, were interviewed for their perceptions on the use of both nonpharmacological interventions and medications for behavioral disturbances (Kerns, Winter, Winter, Kerns, & Etz, 2017). Caregivers were able to identify three major issues regarding medications for persons with dementia including (a) barriers exist for nonpharmacologic therapies and these should be addressed; (b) medications have few barriers, and seem generally effective and safe; and (c) when nonpharmacologic measures fail, medications, including antipsychotics, may be necessary and appropriate to relieve the person with dementia's distress. This study highlights the important voice that caregivers, both family members and nurses, can bring to person-centered care (Kerns, Winter, Winter, Kerns, & Etz, 2017).

As noted above, medications can be the cause of newly developing behavioral disturbances among persons living with dementia. The astute family member and nonphysician care provider should be suspicious when a new or concerning behavior occurs soon after a new medication has been started. Similarly, concern should be raised if the person living with dementia develops new behavioral symptoms and may not be receiving their medications as they have been prescribed, either because the medicine is being taken at the wrong dose or it is being taken too frequently, not frequently enough, or at the wrong times. As adults age, their bodies process medications differently than they did when they were younger and as a result, there are medications that some persons living with dementia have taken for years but no longer tolerate as their body ages and as their brains become more vulnerable with the worsening of their condition. Of particular concern is the use of anticholinergic medications in older adults and the negative impact on cognitive function. A review of the literature by [Boustani and colleagues \(2008\)](#) found that prescribing anticholinergics to older adults can lead to acute cognitive impairment and might even lead to chronic cognitive deficitis ([Boustani, Campbell, Munger, Maidment, & Fox, 2008](#)). Given changes in responses to medication over time, it is very important for family members and/or nonphysician care providers to attend routine doctors' appointments with the person living with dementia; to make sure that they bring all medications, supplements, and herbs with them to the appointments whether these are prescribed or taken over-the-counter; and that they discuss with the person's physician whether all of the medications continue to be needed. The physician should welcome this type of information and these types of conversations as they help the family and nonphysician care providers deliver care that is personalized and appropriate to the needs of the person living with dementia. Physicians and other medical care providers that are not welcoming or supportive of person-centered care for the person living with dementia and participatory care with the family caregiver, may not be the most appropriate provider for the person with dementia and caregiver dyad.

Family caregivers and nonphysician care providers should expect that the medical provider will start with the lowest effective dose of a medication then reevaluate the person living with dementia for anticipated side effects and effectiveness of the medication before deciding whether to continue the medicine, increase its dose, or discontinue it. A useful tool to consult when evaluating the need to start, continue, or discontinue a medication for an older adult and particularly those with dementia is the Beers List ([AGS, 2015](#)). This list, originally developed by physician Mark Beers in 1991 and updated most recently in 2012, includes 34 medicines and classes of medicines that are "potentially inappropriate" in older adults. Examples of these include benzodiazepines, like lorazepam which may be used to address anxiety but can increase the risk

of falls or confusion in an older adult, or anticholinergic medications, like diphenhydramine which may be used to treat allergic symptoms in an urgent or emergent situation but can cause confusion or fatigue in a vulnerable senior and should not be used for treating either sleep issues or anxiety. Asking medical providers about the necessity of all prescribed medicines and understanding the indication for their use can be an important way for family caregivers and nonphysician care providers to be effective advocates for persons living with dementia.

While medicines are clearly an important precipitant of behavioral disturbances among older adults, there are other important causes to consider. Pain is obviously still experienced by persons living with dementia though in more advanced stages of the condition the person's reporting of pain may be impaired, take a different form, or be unrecognized by others. In this situation, the report of a family caregiver or nonphysician care provider about increased irritability or grimacing during certain activities or at certain times of the day can be an important clue to pain's role in the person's behavior. To overcome the difficulty of the person living with dementia communicating their pain, it has been recommended that observational scales that help gauge the level of person's pain be used. One such example, the PAINAD scale asks providers to observe and rate person's outward behaviors across six domains that may correlate with the presence of pain: Breathing, negative vocalizations, facial expression, body language, and consolability (<https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf>). While any observational pain scale may rely to some extent on the skill of the observer and so necessarily require some training on the part of the examiner, this approach nonetheless remains a valid attempt to overcome the communication difficulties that many persons living with dementia experience as the condition advances ([Rosenberg & Lyketsos, 2011](#)). Research by [Husebo and colleagues \(2011\)](#) that measured and treated pain in a large sample of nursing home residents with late stage dementia, showed that significant results in reducing pain and agitation were found with a relatively simple intervention and protocol that has been long approved by the [American Geriatrics Society \(1998\)](#). Developing an effective approach to the management of pain among persons living with dementia does not need to be complicated or to rely on the use of powerful pain control medications such as opioids; pain can potentially be controlled with milder medications that do not come with significant side effects at usual doses. Similarly, there is evidence that the use of acetaminophen, the main ingredient in a common over-the-counter pain medicine, can decrease agitation among persons living with dementia ([Corbett et al., 2012](#)).

Other common causes of behavioral disturbances among persons living with dementia can include exposure to frightening stimuli, sleep disruption, and the development of delirium. Frightening or misunderstood stimuli can lead to behavioral disturbances that occur with bathing

or with cleaning after toileting. Others, whether brought on by persons that remind the older adult of an unpleasant former acquaintance or that cause confusion, can take more detective work to identify. In either event, identifying the cause and thus the meaning of the concerning behavior can be the first step in developing a plan to manage it (Rasin & Barrick, 2004).

Sleep disruptions are common and can be exacerbated by disruptions in person's normal internal 24-hr clock, the circadian rhythm (Deschenes & McCurry, 2009; Dauvilliers, 2007). Cross-sectional studies have suggested that approximately 25%–35% of persons with Alzheimer's disease have problems sleeping, and most likely due to the progressive deterioration and loss of neurons in the suprachiasmatic nucleus (Dauvilliers, 2007). Unfortunately, medications commonly used to treat negative behavioral symptoms of dementia and to slow disease progressions, often result in negative side effects that affect sleep and wakefulness (Dauvilliers, 2007; Wu & Swaab, 2007). Setting a consistent schedule, promoting a regular nighttime routine, finding a comfortable sleeping space without excess noise, temperature, or light can all be initial steps that families and nonphysician care providers take to address this issue (Deschenes & McCurry, 2009; Wu & Swaab, 2007). Finally, delirium is a condition in which persons, particularly those with dementia or other conditions which make their brains more vulnerable, typically display new and fluctuating symptoms of inattention and either disorganized thinking or altered levels of consciousness. If this condition is suspected, it is recommended that a family member or nonphysician care provider bring the condition to the medical provider's attention, as further medical testing and observation may be warranted.

Nonpharmacologic Interventions

Behavioral and psychological symptoms of dementia (BPSD) may become necessary. BPSD is a term used to describe a heterogeneous range of psychological reactions, psychiatric symptoms, and behaviors occurring in people with dementia of any etiology (Finkel & Burns, 2000). Managing BPSD is critical because the incidence of these have been shown to result in premature institutionalization, increased financial cost, increased caregiver burden, poor quality of life for the person with dementia and their family caregiver as well as increased nursing stress (de Vugt et al., 2005; Draper et al., 2011; Herrmann et al., 2006; International Psychogeriatrics Association, 2000). The majority of persons living with dementia (75%–98%) develop some behavioral or psychiatric symptoms at some point in their illness (Ballard & Waite, 2006; Fung et al., 2012; Sink, Covinsky, Newcomer, & Yaffe, 2004; Teri et al., 2000).

When providing care for a person living with dementia, nonpharmacological interventions are preferred and should be tried first. Research on the effectiveness of

nonpharmacological interventions has increased over the past few years and the interventions discussed below have shown positive impact on both the person living with dementia and the family caregiver. Indeed, a recent systematic review of systematic reviews in this area, found that while methodologies and sample sizes vary, music therapy and behavioral management techniques proved most beneficial overall (Abraha et al., 2017). In addition, Gitlin, Kales, & Lyketsos (2012) stress that nonpharmacologic interventions need to be included as first-line treatment for behavioral disturbances, or in conjunction with pharmacologic treatments if necessary.

Activity and recreation have been shown to be beneficial to the person living with dementia. Encouraging participation in daily chores and maintaining hobbies and shared past activities have been shown to improve mood, reduce agitation, and improve quality of life for persons living with dementia. Twenty to sixty minutes of activity daily with skill level and interest well matched to that of the person living with dementia have been shown to have the most benefit (de Oliveira et al., 2015; Kolanowski, Litaker, & Buettner, 2005).

Educating family caregivers has been shown to be as effective at reducing agitation as medications (de Oliveira et al., 2015; Teri et al., 2000). Among the important things for family caregivers to learn is that a person living with dementia does not behave in these ways intentionally. Rather, the behaviors are manifestations of a brain disorder, and caregivers should not take personally anything the person living with dementia says or does (Guerrero Austrom, Lu, & Hendrie, 2013). Knowing this can help avoid conflicts, anger, and subsequent feelings of guilt. Persons living with dementia cannot be held responsible for their behaviors, but all behavior has a purpose. It is up to the family caregiver to look for that underlying purpose. For example, a person living with dementia may be agitated and wander around the house because he has forgotten where the bathroom is and he needs to use it. Or a person with dementia may constantly disrobe because she is too hot. The family caregiver should not blame the person living with dementia for these behaviors but should remain calm, try to figure out what is causing the behavior, and redirect the person living with dementia while protecting his or her dignity (Guerrero Austrom et al., 2013; Whitlatch, Judge, Zarit, & Femia, 2006). Nonphysician care providers can help to remind family caregivers that the person with dementia is no longer acting with volition. Several psychosocial educational programs have been shown to be effective in increasing caregiver knowledge and understanding of person's with dementia's behaviors and challenges (Burns et al., 2003; Falcão, Bras, Garcia, Santo, & Nunez, 2015; Gitlin et al., 2012) leading to improved outcomes for both caregivers and patients. Care providers are encouraged to direct family caregivers to available resources (<http://www.alz.org/care>; <https://www.nia.nih.gov/alzheimers>; <https://cicoa.org/services/careaware>; <http://www.actonalz.org/dementia-friendly-toolkit>).

A person living with dementia will need care for many years. Successful caregiving is based on understanding the caregiver's emotional response to the disease, to the person living with dementia, and to the behaviors, which all change over time. Families must endure an ongoing grief process as they strive to cope with the demands of caregiving while watching the psychological death of their loved one and the death of that individual's personality—that quality or assemblage of qualities that makes a person who he or she is. Many caregiving families fail to realize that grief is an appropriate response when caring for a person with dementia (Austrom & Lu, 2009; Ott, Sanders, & Kelber, 2007; Schulz et al., 2012). Nonphysician care providers play an important role in supporting families as they grieve.

Exercise programs also have been shown to be beneficial in reducing agitation. In one study, persons with dementia who participated in a 3-week group exercise program for 30 min per day (15 min of aerobic exercise and 15 min of resistance training) showed reduced agitation (Aman & Thomas, 2009; de Oliveira et al., 2015).

Pharmacologic Interventions

Despite best intentions, pharmacologic management of the behavioral and psychological symptoms of dementia (BPSD) may become necessary. BPSD is a term used to describe a heterogeneous range of psychological reactions, psychiatric symptoms, and behaviors occurring in people with dementia of any etiology (Finkel & Burns, 2000). Managing BPSD is critical because the incidence of these have been shown to result in premature institutionalization, increased financial cost, increased caregiver burden, poor quality of life for the person with dementia and their family caregiver as well as increased nursing stress (de Vugt et al., 2005; Draper et al., 2011; Herrmann et al., 2006; International Psychogeriatrics Association, 2000). As many as 90% of persons living with dementia develop some behavioral or psychiatric symptoms at some point in their illness (Ballard & Waite, 2006; Fung et al., 2012).

It is important for nonphysician care providers to understand the basics of medications used to treat symptoms in person living with dementia. There is a role for the use of medications in the management of the progression of persons' dementia as well as the management of their comorbid illnesses. Any time that a medication is going to be used in an older adult, a careful assessment of the risks and benefits of the medication's use is warranted with due consideration given to the goals of the person's care and the stage of their dementia. Dementia-specific medications, such as acetylcholinesterase inhibitors and NMDA agonists, have received approval from the U.S. Food and Drug Administration (FDA) to treat cognitive symptoms associated with Alzheimer's disease. These medications are prescribed with an aim of decreasing the rate of cognitive decline associated with the disease. No medications are

currently approved for the treatment of the behavioral and psychological symptoms associated with Alzheimer's disease. Indeed, any medications prescribed by a physician for treatment of these symptoms are "off label," an approach in which a provider administers a medication for a reason other than the one for which the medicine was approved for use by the FDA.

Common medications that are used "off label" to treat the behavioral and psychological symptoms of dementia include antidepressant medicines, which are thought to target mood disturbances and agitation, benzodiazepines to target anxiety, and antipsychotic medications for the treatment of hallucinations, agitation, and aggressive behavior. It should be noted that there has been particular concern raised by the use of antipsychotic medications among persons with dementia given research that is shown an increased risk of stroke and death associated with their use (Douglas and Smeeth, 2008; Gill et al., 2007; Schneeweiss, Setoguchi, Brookhart, Dormuth, & Wang, 2007). As a result, the FDA has issued a "black box warning" that warns providers about the increased risks that accompany use of these medicines. Careful evaluation, discussion with caregivers, and monitoring of persons with dementia would be warranted if use of antipsychotic medications were to be initiated. As with any medication started for an older adult, it is recommended that the need for continued use of these medications is reviewed periodically, that attempts be made to decrease their dose, and their use be discontinued when possible. As always, nonpharmacologic approaches to the management of dementia symptoms are preferred and it should be considered that the concurrent use of nonpharmacologic approaches may decrease or eliminate the need for use of prescribed medications to address concerning behaviors. It is important for nonphysician care providers to understand the basics of medications used to treat symptoms in person living with dementia.

Crisis Planning and Management

Compared to older adults without dementia, persons with dementia visit the emergency department (ED) more frequently, are hospitalized more often, return to the ED within 30 days of an initial ED visit at higher rates, and are at higher risk of death in the six months after an ED visit than persons without dementia (LaMantia, Stump, Messina, Miller, & Callahan, 2016). These data underscore the vulnerable state of persons living with dementia who develop an acute illness. Preparing for a crisis before it occurs can be an important step that caregivers and community care providers take to ensure that persons living with dementia receive optimal care.

One of the most important steps that family caregivers can and should take to ensure that they are able to represent the person living with dementia is to participate in advance care planning discussions early in the state of the illness, while substantive conversations about wishes can

still be had. While many states recognize the right of family members to make medical decisions for loved ones when they can no longer speak for themselves and have established clear hierarchies of precedence for delegating decision making powers among relatives, not every state does so. As a result, it can be useful to establish a durable health care power of attorney designation early on in the course of the person's illness. Forms to complete these designations are often available through state and local governments, local hospitals, and elder care attorneys. Forms frequently need to be notarized and may need to be filed with a local authority, depending on the jurisdiction, so it is recommended to verify the appropriate procedures for setting this in place with an entity familiar with local laws and regulation. For individuals who learn that they are to be or seek to become someone's health care power of attorney, it is important that they speak with the person living with dementia about their health care values and wishes so that the person's values and decisions can be represented if/when that time comes. While these conversations may be difficult to initiate, they are critical to have and many guidelines and materials are available on-line to help advise people on how to approach these (<http://www.alz.org/care/alzheimers-dementia-legal-documents.asp>; <http://www.nia.nih.gov/alzheimers/legal-and-financial-issues-people-alzheimers-disease-resource-list>). Nonphysician care providers can be a support to families as they navigate the process.

End-of-life Care

From these conversations, it may become clear that the person living with dementia may wish to place limitations on the type of care that they receive if they were to become ill. In some areas, it may be possible to discuss end-of life care decisions with the physician or other medical care provider whether or not the person with dementia and their health care representative wish to put in place a do not resuscitate order often called a DNR, that would direct emergency services personnel not to start resuscitation in the event that the person living with dementia were to experience cardiac arrest or needs assistance in breathing. Importantly, these orders still allow Medical care providers to offer treatments that would keep the person living with dementia comfortable, but without interrupting the natural course of events. If a person were to have more specific ideas about the type of care they would like to receive, in many states they may elect to complete Physician Orders for Life-Sustaining Treatment (POLST) with their provider (Hickman, Nelson, Smith-Howell, & Hammes, 2014). These forms, when completed, help delineate what types of care persons with serious illnesses seek to receive and forego towards the end of their lives.

Beyond these considerations, caregivers may wish to keep critical materials, including lists of medications, active medical conditions, names of treating providers, together in a folder that is easily accessible and can be brought to the emergency department or hospital if the person with dementia needs emergency care. Given that persons with

dementia may have a hard time navigating an emergency department or staying in a hospital room on their own, it may be necessary for their caregivers to stay by their bedside to serve as their advocate, provide comfort to them, and explain to them what is happening. Such tasks can be exhausting and many caregivers find it helpful to establish a network of friends and family who potentially can rotate serving in these roles if extended medical care is needed. Negotiating networks of people who would be willing to step in if the need were to arise ahead of time can be useful to maximize the likelihood that these tasks do not fall back on one person, who may become easily overwhelmed. Again, nonphysician care providers can be a huge support to families as they plan for end of life care and decisions.

Summary and Conclusions

On-going medical management for persons living with dementia is complex and can last for many years. Helping persons living with dementia and their family caregivers negotiate the medical maze over the course of the disease can reduce stress, improve care and the quality of life for both persons with dementia and their caregivers.

Recommendations for ongoing medical management to maximize health and well-being for persons living with dementia

Nonphysician care providers who work with persons living with dementia and their families in community or residential care settings should:

1. Take a holistic, person-centered approach to care and embrace a positive approach to the support for persons living with dementia and their caregivers that acknowledges the importance of individuals' ongoing medical care to their well-being and quality of life. Nonphysician care providers must adopt a holistic approach to providing care and ongoing support to the person living with dementia and their family caregivers. They should work to reduce existing barriers to coordination of medical and nonmedical care and support. Adopting a positive approach towards care can reduce real or perceived messages of hopelessness and helplessness and replace these with positive messages and an approach that encourages persons living with dementia and their caregivers to seek support and care over the course of the disease.
2. Seek to understand the role of medical providers in the care of persons living with dementia and the contributions that they make to care. Nonmedical care providers and family caregivers should work with medical providers towards developing a shared vision of care to support the person living with dementia.
3. Know about common comorbidities of aging and dementia and encourage persons living with dementia and their families to talk with the person's physician about how to manage comorbidities at home or in residential care

settings. Common comorbidities can negatively impact a person living with dementia, and conversely, a diagnosis of dementia can make the treatment and management of comorbid conditions quite challenging. Nonmedical care providers should encourage persons living with dementia and their families to report acute changes in health and function to the person's physician, and to let the physician know about difficulties they encounter in managing acute and chronic comorbidities at home or in a residential care facility.

4. Encourage persons living with dementia and their families to use nonpharmacologic interventions for common behavioral and psychological symptoms of dementia first. Increasing evidence suggests nonpharmacological interventions are effective at managing behavioral and psychological symptoms of dementia. Community care providers should encourage persons with dementia and their families to try these interventions first before considering pharmacological treatments.
5. Understand and support the use of pharmacological interventions when they are necessary for the person's safety, well-being, and quality of life. Although nonpharmacological interventions are preferred, there are times when pharmacological treatment is warranted for behavioral and psychological symptoms. It is important for community care providers to understand that pharmacological treatment can have value for the person living with dementia in certain situations and to help them and their family caregiver to accept such treatment. Community care providers should also understand the general principles for starting and more importantly, ending pharmacological treatments and encourage the person living with dementia and family caregivers to ask their medical providers for regular medication reviews and to consider the discontinuation of medications when appropriate.
6. Work with the person living with dementia, the family, and the person's physician to create and implement a person-centered plan for possible medical and social crises. It is helpful for persons living with dementia and their caregivers to have a plan in place should a medical or social crisis occur, such as an illness, hospitalization or the death of a caregiver. Having a plan in place will help the person's physician and community care providers provide care and support that reflects the preferences of the person living with dementia and reduce stress for family members and care providers who have to make decisions for the person during a crisis.
7. Encourage persons living with dementia and their families to start end-of-life care discussions early. Persons living with dementia and their caregivers should understand options available for care during the later stages of Alzheimer's disease. Having discussions early with the person's physician and other care providers and communicating the preferences of the person and family across care settings can make the transitions during the progression of dementia more manageable.

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Conflict of Interest

None reported.

References

- Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M.,...Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series. *BMJ Open*, *7*, e012759. doi:10.1136/bmjopen-2016-012759
- Aman, E., & Thomas, D. R. (2009). Supervised exercise to reduce agitation in severely cognitively impaired persons. *Journal of the American Medical Directors Association*, *10*, 271-276. doi:10.1016/j.jamda.2008.12.053
- American Geriatrics Society 2015 Beers Criteria Update Expert Panel. (2015). American Geriatrics Society updated beers criteria for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society*, *63*, 2227-2246.
- American Geriatrics Society. (1998). The management of chronic pain in older persons: AGS Panel on Chronic Pain in Older Persons. *Journal of the American Geriatric Society*, *46*, 635-651. doi:10.1111/j.1532-5415.1998.tb01084
- Austrom, M. G., & Lu, Y. (2009). Long term caregiving: Helping families of persons with mild cognitive impairment cope. *Current Alzheimer Research*, *6*, 392-398. doi:10.2174/156720509788929291
- Ballard, C., & Waite, J. (2006). The effectiveness of atypical antipsychotics for the treatment of aggression and psychosis in Alzheimer's disease. *Cochrane Database of Systematic Reviews*, *25*, CD003476 doi:10.1002/14651858.CD003476.pub2.
- Boustani, M., Sachs, G., & Callahan, C. M. (2007). Can primary care meet the biopsychosocial needs of older adults with dementia? *Journal of General Internal Medicine*, *22*, 1625-1627. doi:10.1007/s11606-007-0386-y
- Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M.,...Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health*, *15*, 13-22. doi:10.1080/13607863.2010.496445
- Boustani, M., Campbell, N., Munger, S., Maidment, I., & Fox, C. (2008). Impact of anticholinergics on the brain: A review and practical application. *Aging Health*, *4*: 11-20. doi:10.2217/1745509X.4.3.311
- Bunn, F., Burn, A. M., Goodman, C., Rait, G., Norton, S., Robinson, L.,...Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, *12*, 192. doi:10.1186/s12916-014-0192-4
- Burns, R., Nichols, L. O., Martindale-Adams, J., Graney, M. J., & Lummus, A. (2003). Primary care interventions for

- dementia caregivers: 2-year outcomes from the REACH study. *The Gerontologist*, *43*, 547–555. doi:10.1093/geront/43.4.547
- Callahan, C. M. (2017). Alzheimer's disease: Individuals, dyads, communities, and costs. *Journal of the American Geriatrics Society*, *65*, 892–895. doi:10.1111/jgs.14808
- Callahan, C. M., Boustani, M. A., Weiner, M., Beck, R. A., Livin, L. R., Kellams, J. J.,...Hendrie, H. C. (2011). Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging & Mental Health*, *15*, 5–12. doi:10.1080/13607861003801052
- Callahan, C. M., Sachs, G. A., Lamantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs (Project Hope)*, *33*, 626–632. doi:10.1377/hlthaff.2013.1260
- Callahan, C. M., Boustani, M. A., Schmid, A. A., Austrom, M. G., Miller, D. K., Gao, S.,...Hendrie, H. C. (2012). Alzheimer's disease multiple intervention trial (ADMIT): Study protocol for a randomized controlled clinical trial. *Trials*, *13*, 92. doi:10.1186/1745-6215-13-92
- Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews. Neurology*, *8*, 264–274. doi:10.1038/nrneuro.2012.53
- Dauvilliers, Y. (2007). Insomnia in patients with neurodegenerative conditions. *Sleep Medicine*, *8*(Suppl. 4), S27–S34. doi:10.1016/S1389-9457(08)70006-6
- Deschenes, C. L., & McCurry, S. M. (2009). Current treatments for sleep disturbances in individuals with dementia. *Current Psychiatry Reports*, *11*, 20–26.
- de Oliveira, A. M., Radanovic, M., de Mello, P. C., Buchain, P. C., Vizzotto, A. D., Celestino, D. L.,...Forlenza, O. V. (2015). Nonpharmacological interventions to reduce behavioral and psychological symptoms of dementia: A systematic review. *BioMed Research International*, *2015*, 218980. doi:10.1155/2015/218980
- de Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., & Verhey, F. R. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics*, *17*, 577–589. doi:10.1017/S1041610205002292
- Douglas, I. J., & Smeeth, L. (2008). Exposure to antipsychotics and risk of stroke: Self controlled case series study. *BMJ (Clinical Research ed.)*, *337*, a1227. doi:10.1136/bmj.a1227
- Draper, B. M., Finkel, S. I., and Tune, L. (2011). Module 1: An introduction to BPSD. (pp 1.1-1.16). In B. M., Draper, H., Brodaty, and S. I., Finkel (Eds) *IPA Complete Guides to the Behavioral and Psychological Symptoms of Dementia (BPSD)—Specialist Guide*. Chicago, IL: International Psychogeriatric Association.
- Falcão, D. V., Braz, M. C., Garcia, C. R., Santo, G. D., & Nunez, P. V. (2015). Psychosocial and educational interventions for family caregivers of seniors with Alzheimer's disease. *The Gerontologist*, *55*(Suppl. 2), 661. doi:10.1093/geront/gnv345.06
- Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2007). Efficacy of behavioral interventions for dementia caregivers. *Western Journal of Nursing Research*, *29*, 944–960. doi:10.1177/0193945907303084
- Finkel, S. I., & Burns, A. (2000). *International Consensus Conference on Behavioral Disturbances of Dementia 1999, International Psychogeriatrics, 2000*. Chicago: IPA.
- Flaherty, J. H., & Little, M. O. (2011). Matching the environment to patients with delirium: Lessons learned from the delirium room, a restraint-free environment for older hospitalized adults with delirium. *Journal of the American Geriatrics Society*, *59*(Suppl. 2), S295–S300. doi:10.1111/j.1532-5415.2011.03678.x
- Fowler, N. R., Boustani, M. A., Frame, A., Perkins, A. J., Monahan, P., Gao, S.,...Hendrie, H. C. (2012). Effect of patient perceptions on dementia screening in primary care. *Journal of the American Geriatrics Society*, *60*, 1037–1043. doi:10.1111/j.1532-5415.2012.03991.x
- Fung, C. H., Martin, J. L., Chung, C., Fiorentino, L., Mitchell, M., Josephson, K. R.,...Alessi, C. (2012). Sleep disturbance among older adults in assisted living facilities. *The American Journal of Geriatric Psychiatry*, *20*, 485–493. doi:10.1097/JGP.0b013e318252e3e0
- Gill, S. S., Bronskill, S. E., Normand, S. L., Anderson, G. M., Sykora, K., Lam, K.,...Rochon, P. A. (2007). Antipsychotic drug use and mortality in older adults with dementia. *Annals of Internal Medicine*, *146*, 775–786. doi:10.7326/0003-4819-146-11-200706050-00006
- Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*, *308*, 2020–2029. doi:10.1001/jama.2012.36918
- Guerriero Austrom, M., Lu, Y., & Hendrie, H. C. (2013). Family care for elders with dementia. In E. A. Capezuti, M. L. Malone, P. R. Katz, & M. Mezey (Eds.), *The encyclopedia of elder care: The comprehensive resource on geriatric and social care* (3rd ed., pp. 286–289). New York: Springer Publishing Company.
- Herrmann N., Lanctôt, K.L., Sambrook, R., Lesnikova, N., Hébert, R., McCracken, P.,...Nguyen, E. (2006). The contribution of neuropsychiatric symptoms to the cost of dementia care. *International Journal of Geriatric Psychiatry*, *21*, 972–976. doi:10.1002/gps.1594
- Hickman, S. E., Nelson, C. A., Smith-Howell, E., & Hammes, B. J. (2014). Use of the Physician Orders for Life-Sustaining Treatment program for patients being discharged from the hospital to the nursing facility. *Journal of Palliative Medicine*, *17*, 43–49. doi:10.1089/jpm.2013.0097
- Husebo, B. S., Ballard, C., Sandvik, R., Nilsen, O. B., & Aarsland, D. (2011). Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ (Clinical Research ed.)*, *343*, d4065. doi:10.1136/bmj.d4065
- <http://www.actonalz.org/dementia-friendly-toolkit>.
- <https://www.nia.nih.gov/alzheimers>.
- <http://www.alz.org/care>.
- <http://www.alz.org/care/alzheimers-dementia-legal-documents.asp>.
- <https://cicoa.org/services/careaware>.
- <https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf>.
- International Psychogeriatrics Association. (2000). *Complete Guide to Behavioral and Psychological Symptoms of Dementia (BPSD)*. Skokie, IL: IPA.
- Inouye, S. K., & Charpentier, P. A. (1996). Precipitating factors for delirium in hospitalized elderly persons. Predictive model and interrelationship with baseline vulnerability. *JAMA*, *275*, 852–857.

- Inouye, S. K. (1999). Predisposing and precipitating factors for delirium in hospitalized older patients. *Dementia and Geriatric Cognitive Disorders*, *10*, 393–400. doi:10.1159/000017177
- Kerns, J. W., Winter, J. D., Winter, K. M., Kerns, C. C., & Etz, R. S. (2017). Caregiver perspectives about using antipsychotics and other medications for symptoms of dementia. *The Gerontologist*. doi:10.1093/geront/gnx042.
- Kolanowski, A. M., Litaker, M., & Buettner, L. (2005). Efficacy of theory-based activities for behavioral symptoms of dementia. *Nursing Research*, *54*, 219–228.
- LaMantia, M. A., Stump, T. E., Messina, F. C., Miller, D. K., & Callahan, C. M. (2016). Emergency department use among older adults with dementia. *Alzheimer Disease and Associated Disorders*, *30*, 35–40. doi:10.1097/WAD.0000000000000118
- LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G.,...Boustani, M. A. (2015). The aging brain care medical home: Preliminary data. *Journal of the American Geriatrics Society*, *63*, 1209–1213. doi:10.1111/jgs.13447
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R. Jr, Kawas, C. H.,...Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*, 263–269. doi:10.1016/j.jalz.2011.03.005
- Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *The Gerontologist*, *47*, 798–809. doi: 10.1093/geront/47.6.798
- Ragneskog, H., Bråne, G., Karlsson, I., & Kihlgren, M. (1996). Influence of dinner music on food intake and symptoms common in dementia. *Scandinavian Journal of Caring Sciences*, *10*, 11–17. doi:10.1111/j.1471-6712.1996.tb00304
- Rasin, J., & Barrick, A. L. (2004). Bathing patients with dementia: Concentrating on the patient's needs rather than merely the task. *The American Journal of Nursing*, *104*, 30–32.
- Rosenberg, P. B., & Lyketsos, C. G. (2011). Treating agitation in dementia. *BMJ (Clinical Research ed.)*, *343*, d3913. doi:10.1136/bmj.d3913
- Schneeweiss, S., Setoguchi, S., Brookhart, A., Dormuth, C., & Wang, P. S. (2007). Risk of death associated with the use of conventional versus atypical antipsychotic drugs among elderly patients. *Canadian Medical Association Journal*, *176*, 627–632. doi:10.1503/cmaj.061250
- Schubert, C. C., Boustani, M., Callahan, C. M., Perkins, A. J., Carney, C. P., Fox, C.,...Hendrie, H. C. (2006). Comorbidity profile of dementia patients in primary care: Are they sicker? *Journal of the American Geriatrics Society*, *54*, 104–109. doi:10.1111/j.1532-5415.2005.00543.x
- Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging & Mental Health*, *16*, 712–721. doi:10.1080/13607863.2011.651439
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S.,...Belle, S. H.; Resources for Enhancing Alzheimer's Caregiver Health Investigators. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal of Medicine*, *349*, 1936–1942. doi:10.1056/NEJMsa035373
- Sink, K. M., Covinsky, K. E., Newcomer, R., & Yaffe, K. (2004). Ethnic differences in the prevalence and pattern of dementia-related behaviors. *Journal of the American Geriatrics Society*, *52*, 1277–1283. doi:10.1111/j.1532-5415.2004.52356.x
- Tan, Z. S., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large academic health system. *Health Affairs (Project Hope)*, *33*, 619–625. doi:10.1377/hlthaff.2013.1294
- Teri, L., Logsdon, R. G., Peskind, E., Raskind, M., Weiner, M. F., Tractenberg, R. E.,...Thal, L. J.; Alzheimer's Disease Cooperative Study. (2000). Treatment of agitation in AD: A randomized, placebo-controlled clinical trial. *Neurology*, *55*, 1271–1278. http://www.neurology.org/content/55/9/1271
- Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*, *46*, 688–694. doi:10.1093/geront/46.5.688
- Wilkinson, H., & Milne, A. J. (2003). Sharing a diagnosis of dementia—learning from the patient perspective. *Aging & Mental Health*, *7*, 300–307. doi:10.1080/1360786031000120705
- Wu, Y. H., & Swaab, D. F. (2007). Disturbance and strategies for reactivation of the circadian rhythm system in aging and Alzheimer's disease. *Sleep Medicine*, *8*, 623–636. doi:10.1016/j.sleep.2006.11.010