



Primary Palliative Care in Dementia

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Abstract

Primary palliative care is a fundamental aspect of high-quality care for patients with a serious illness such as dementia. The clinician caring for a patient and family suffering with dementia can provide primary palliative care in numerous ways. Perhaps the most important aspects are high quality communication while sharing a diagnosis, counseling the patient through progression of illness and prognostication, and referral to hospice when appropriate. COVID-19 presents additional risks of intensive care requirement and mortality which we must help patients and families navigate. Throughout all of these discussions, the astute clinician must monitor the patient's decision making capacity and balance respect for autonomy with protection against uninformed consent. Excellent primary palliative care also involves discussion of deprescribing medications of uncertain benefit such as long term use of cholinesterase inhibitors and memantine and being vigilant in the monitoring of pain with its relationship to behavioral disturbance in patients with dementia. Clinicians should follow a standardized approach to pain management in this vulnerable population. Caregiver burden is high for patients with dementia and comprehensive care should also address this burden and implement reduction strategies. When these aspects of care are particularly complex or initial managements strategies fall short, palliative care specialists can be an important additional resource not only for the patient and family, but for the care team struggling to guide the way through a disease with innumerable challenges.

Keywords Alzheimer disease · Dementia · Communication · Palliative care · Prognostication · Counseling

Introduction

Palliative care is an interdisciplinary approach to family centered care focusing on improving quality of life and pursuing goal concordant care through measures including expert symptom management, high quality communication, and assistance navigating complex medical decisions [1]. This form of care is appropriate for all patients with serious illnesses and becomes even more essential as an underlying illness advances and fewer effective disease modifying therapies are available. Consequently, palliative care has an important role to play in the care of patients with dementia and their families who face a myriad of symptoms and

progressive functional decline. Furthering this point, palliative care is increasingly entering the discussion of care for neurology patients on a national level [2]. “Primary palliative care” is the skill set all clinicians should develop in order to manage symptoms and guide discussions about prognosis, suffering, and planning for the future. This is distinguished from specialty palliative care focusing on complex cases where initial symptomatic treatments fail or communication and decision making dynamics are particularly challenging [3]. In this article, we will focus on primary palliative care skills for the healthcare provider seeing patients with dementia in addition to a number of thresholds for specialist palliative care referral. We will begin with a review of tools and techniques for managing the difficult conversations we are often faced with in caring for people with dementia and their families. We will transition into a review of prognostication and how that leads into advance care planning, including when and why to refer to hospice. Next, we will discuss management strategies to promote quality of life in this population. To date, studies of quality of life in patients with dementia have shown complex results

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that differ according to whether the patient is self-reporting, the measure is proxy reported, and what specific measure is being used. At the least, evidence strongly indicates that comorbid conditions like depression can have a deleterious effect on quality of life in persons with dementia, highlighting the importance of a holistic approach to care as opposed to a narrow focus on cognition and function [4, 5]. Treatment of high burden neuropsychiatric symptoms will be covered separately in this issue [6]. Finally, we will conclude with a focus on deprescribing and pain management in this complex population.

Communication and Counseling

Providers evaluating and managing patients with cognitive impairment are faced with the frequent and challenging task of breaking a diagnosis of neurodegenerative disease to a patient and their family. The benefits of high quality communication have been well described in other populations and this initial discussion with the patient and family about the diagnosis of dementia represents a major opportunity to improve outcomes such as adjustment to illness and treatment adherence [7]. While telling someone they or their loved one has Alzheimer disease or another neurodegenerative disease is difficult and takes practice as a clinician, with intentional communication skills this conversation can improve rapport and allow patients and their families to develop a specific plan to address their problem. This naming and resolution of uncertainty may in itself provide some relief. In addition, the American Academy of Neurology (AAN) emphasizes quality communication in their 2020 Outcome Quality Measurement Set and the Accreditation Counsel for Graduate Medical Education (ACGME) neurology milestones emphasize communication and compassion as fundamental skills to master in training [8, 9]. These data indicate the need for an organized and effective method of breaking bad news and communicating empathy with patients and their families. In neurodegenerative diseases the diagnosis may not always be certain from the initial evaluation but there is often a strong clinical probability of a specific condition. In these circumstances, starting the counseling conversation by assessing whether the patient prefers to know only definitive diagnoses or they prefer to know the most likely condition being considered is a helpful way to gauge how much information to cover. In patients with significant memory impairment it is particularly crucial to ensure other family/caregivers are present for the counseling to retain the information shared. The SPIKES model offers a systematic approach to breaking bad news [10]. The first step - "S" - is set up and involves ensuring the major stakeholders are present, the conversation occurs

sitting in a quiet and private place, and the essential data has been gathered and reviewed prior to the discussion. The "P" stands for perception; the provider can begin by asking the patient or family to share what they have heard about the cause of their symptoms from other sources. This helps establish the patient and family's level of health literacy and also may identify any previously established misconceptions about their condition. It is not unusual for the patient or family to bring up Alzheimer disease as a concern during the perception check, which will help the provider to perform appropriate counseling. For example, it may be a patient with dementia with Lewy bodies who has been told they have Alzheimer disease previously and this knowledge allows the provider to appropriately compare and contrast the diseases for the patient and family. Another common scenario is that a patient has had Alzheimer disease for years and been placed on cholinesterase inhibitors and/or memantine by previous providers, but they only know the disease as "dementia" and have never heard any more specific diagnosis. The "I," "K," and "E," parts of the mnemonic stand for invitation, knowledge, and empathy and are best viewed as a looping segment of the conversation. The clinician should start with a question inviting further information such as "Would you like to hear what I am concerned is the most likely cause of your memory loss?" or "Would you like to hear what the future may hold in this condition?" Knowledge should then be shared in small and digestible fragments, typically no more than a handful of sentences at a time in plain language. Emotion should then be expected and responded to with empathic communication tools. Then, the loop starts again until sufficient information has been covered to satisfy the agenda for the conversation. Asking for invitations for repeat instances of the "IKE" loop allows the provider and patient/family to both have input on the agenda of the conversation. The final "S" is for summary and strategy where the clinician summarizes the most salient points of the conversation in a few sentences and then focuses the patient and family on the next action step [10]. The NURSE mnemonic (Table 1) provides a framework for some of the most common empathic communication tools which should be practiced regularly throughout any difficult conversation [11]. Two simultaneous streams of information occur in a difficult conversation. The first is cognitive data such as the dementia diagnosis, prognosis, and treatment options. The second is emotional data such as the patient and family's fear or sadness at the news being shared, their transference, and the provider's counter-transference [12]. Full engagement in a difficult conversation requires keeping both of these data streams in mind and ensuring that the emotional data stream is attended to with empathic communication [11]. In the age of COVID-19 with an increased use of telehealth visits and masking during clinical encounters, there are additional barriers to high quality communication. The clinician can

Table 1 NURSE mnemonic [11]

Naming	“It’s normal to be upset by the diagnosis of Alzheimer disease.” Name the emotion you see or expect. Don’t be afraid to be wrong.
Understanding	“Thank you for sharing that, it really helps me have a better understanding of where you are coming from.” Focus on understanding as a process not a destination (avoid saying “I understand how you feel”).
Respecting	“At this time I can’t foresee a way that a repeat MRI would be helpful. At the same time, I respect the way you are advocating for your mother and ensuring she gets the best care possible.” Consider respecting statements when you sense tension about the patient/family wanting unnecessary or unproven tests/treatments.
Supporting	“Know that I will do my best to walk this road with you and help find the most effective treatment. You can always reach out to me with more questions by phone.” Supporting statements are a good part of the wrap up to a difficult conversation.
Exploring	“It would help my understanding of your situation to hear more about...” Exploring statements are less an empathic communication tool and more a way of moving the conversation forward to find other opportunities for empathy.

The NURSE mnemonic provides a tool for remembering commonly used empathic communication techniques. These are of particular importance during difficult conversations.

utilize strategies such as exaggerating body language and facial expressions, slow and expressive speech, and simulating eye contact through the camera to improve the quality of communication in these circumstances [13].

Once the work of breaking bad news has been completed there are still further difficult conversations to have in the care of people with neurodegenerative diseases. Advance care planning (ACP) is recognized as a health care priority for individuals with dementia [14]. However, considerable barriers exist to ACP in the dementia population particularly regarding the timing of ACP discussion and advance directive completion with the threat of progressing cognitive decline [15]. Time constraints are another issue commonly identified as a barrier to high quality ACP [16]. In light of these issues, it is essential to reserve time with the patient for counseling and discussion of ACP early on in the management of the patient. Another crucial element of successful ACP is to see this as an ongoing discussion with the patient and family/caregiver, not a single point in time. Several important times in the course of the illness to trigger discussion of ACP are as follows: (1) around the time of diagnosis, (2) with any major change in health, (3) with change of place of residence [17, 18]. Lower threat forms of ACP include designation of a healthcare surrogate and discussion of values and beliefs – what makes life most

meaningful. While “goals of care” is used loosely in medical practice, the process is truly 2 separate elements. The “goal” of medical care should more strictly be defined as the attempt to maximize what the patient and family identify as most important in life. This then directly leads to treatment preferences, which we as providers can help determine using principles of shared decision making based on the aforementioned goals and values. As disease progresses the importance of specific treatment preferences increases, for example views on cardiopulmonary resuscitation and other invasive forms of treatment. In late stages of disease, even hospitalization may be considered a burdensome treatment and preferences about accepting admission to the hospital or avoiding it whenever possible can be elicited. The REMAP communication model (Table 2) offers a useful system for more formally assessing the goals of care and treatment preferences [19]. Note that establishing the true goals of treatment should always precede decisions about treatment preferences and ideally the provider has gained a deep enough understanding of what the patient and family’s hopes and values are to propose a treatment plan during the transition into that phase of the conversation.

Breaking bad news and discussion of ACP both fall into the realm of primary palliative care and are a shared responsibility for all of the providers caring for a patient

Table 2 REMAP Model for Goals of Care Discussion [19]

Reframe	“I’m worried that the recent hospitalization for aspiration pneumonia marks that we have entered an advanced stage of disease. Are you OK with discussing where we go from here?”
Expect emotions	Attend to the emotional data stream and use NURSE mnemonic or other empathic communication tools.
Map out patient goals	“If we knew that time was short, would do you think would be most important?”
Align with goals	Summarize what you have learned about the desired focus of time and medical care.
Propose a plan	“Base on what you have told me is most important, is it alright if I recommend a course of action?”

The REMAP mnemonic provides a tool for remembering a systematic organization to goals of care discussions in patients with serious illnesses.

and family. At the same time, there will be instances when expert palliative care consultation should be considered to assist in these conversations. One threshold to consider palliative care referral would be if there is conflict among the patient, caregivers, and family about the goals of care and treatment preferences. Another would be the identification of persistent incongruity in the care plan, for example a patient who wants to avoid rehospitalization but still wants to receive cardiopulmonary resuscitation, despite initial counseling.

Capacity

Advance care planning in individuals with cognitive impairment has an additional layer of complexity in that at some point in the progression of disease there will be a loss of capacity of the patient to make their own medical decisions, and this often happens much earlier in the progression of disease than in other serious illnesses like cancer and heart failure. Consequently, a thorough discussion of ACP in the dementia population requires examination of the capacity evaluation and the associated complexities. It also once again emphasizes the importance of early ACP. While there is inconsistency in the literature on terminology, we will follow the definitions of decision making capacity as the clinical evaluation regarding a patient's ability to comprehend information surrounding a choice, reason towards a decision, and have insight into the consequences of that decision. Meanwhile, competence is a term typically reserved for legal determinations of decisional ability [20]. We will focus on capacity. The patient must demonstrate four abilities in the assessment of capacity: (1) communicate a choice, (2) understand important information influencing the choice, (3) appreciate the consequences of the choices, and (4) express their reasoning leading to the choice (20). The capacity assessment is not "all or nothing"—it only pertains to a single decision at a single point in time which results in capacity being a fluid concept. Unsurprisingly, there is a high likelihood of failure to meet capacity standards in the Alzheimer disease population, even in the mild to moderate stages [22]. Studies focusing on patients with amnesic MCI have also found milder impairment [23]. These data indicate that the provider must be vigilant in considering decision making capacity throughout the care of individuals with cognitive impairment, particularly when they meet criteria for dementia. In ACP discussions, the stakes are high and a patient simply expressing a choice is not sufficient. The clinician must ensure the discussion has gone deep enough to reflect the other three components of the capacity determination. The patient's understanding of relevant information and consequences of the choices being weighed is effectively addressed by using the teach-back method—asking the patient to express in their own words the information

surrounding the decision [24]. Finally, the patient must be able to articulate a rationale for their decision. Regardless of the outcome of the capacity evaluation, assumptions should not be made about generalization to other decisions or other points in time. Inappropriately depriving patients of their autonomy must not be taken lightly, and when the decision is not urgent and there is uncertainty in the mind of the clinician it can be appropriate to revisit the subject on a separate occasion for a repeat evaluation [21].

Prognostication and Hospice Referral

Prognostication is an important component of high quality counseling and ACP. In order to make an informed decision about what treatment preferences align with a patient's goals it is helpful to reach a shared understanding about what the future might hold and how long the patient may survive. The prognosis is heavily influenced by the age of the patient at diagnosis. In the Baltimore Longitudinal Study of Aging group the median survival time for those diagnosed with Alzheimer disease younger than 75 was 6 years, between the ages of 75 and 84 was 5 years, and at 85 or older was only 3.5 years [25]. Another prospective epidemiological study found that survival was 8.29 years in those diagnosed with Alzheimer disease younger than 75, 5.77 years between the ages of 75–84, and 3.82 years diagnosed age 85 or older [26]. Regarding cause of death, some conditions were equally likely to be listed on the death certificate in both those with or without AD such as stroke in about 10% and sepsis/septicemia in about 5%, while other conditions such as pneumonia (12.3% vs. 6.4%) and dehydration (3% vs. 0%) were much more likely to be listed in those with Alzheimer disease [26]. One prospective study looking at nursing home residents with advanced dementia (defined by a 5 or 6 on the Cognitive Performance Scale and stage 7 on the Global Deterioration Scale) found that 54.8% died over the 18 month follow up duration with a median survival of 478 days. Those who developed pneumonia or a febrile episode had almost a 50% mortality rate in the next 6 months [27].

Literature is scant on prognosis in other forms of dementia. Studies suggest a similar to slightly worse prognosis in vascular dementia [28, 29]. There is heterogeneity in frontotemporal dementia by phenotype, but most forms appear similar in survival to Alzheimer disease except for FTD-ALS with a median survival of 2.77 years in a meta-analysis [30]. Meanwhile, the majority of studies on the prognosis in dementia with Lewy bodies (DLB) show shorter survival than Alzheimer disease with a mean difference of 1.6 years [31].

Hospice eligibility requirements are modeled around a threshold of patients being more likely than not to die in the

next 6 months, and in the case of “Alzheimer’s Disease & Related Disorders” the CMS local coverage determination (LCD) for hospice states the criteria of FAST stage of 7 and beyond in addition to a specific comorbidity or secondary condition [32]. The FAST scale attempts to outline a linear progression of dementia where stage 6 represents loss of many ADLs and the initial stages of stage 7 describe loss of speech and locomotion [33]. Clinicians and scientists have attempted to operationalize these criteria in various ways and found that reliable determination of a 6-month prognosis is elusive in patients with dementia [34–36].

Considering the act of referring to hospice, it is appropriate to have a high sensitivity and relatively lower specificity for eligibility on the part of the referring provider. Even if the initial hospice agency evaluation finds the patient is not eligible they often can be enrolled either into a home-based palliative care program run by that agency or receive periodic check-ins from the hospice team to monitor for markers of progression and reevaluation. In this way, we can think of hospice as an extra support for the patient and family living with advanced dementia and not a last ditch effort at end of life care. For those seeking a hospice philosophy of care accessing this support as early as possible should be the ideal. Evidence supports the benefit, with 73.2% of bereaved family members of a patient with dementia under the care of hospice rating the overall hospice care as excellent [37].

The COVID-19 pandemic has presented another challenge to individuals living with dementia and their families as the disease has a disproportionate burden on this group of patients. Multiple studies have shown that, despite attempts to control for other health conditions, dementia is associated with a higher risk of SARS-CoV-2 infection and mortality after COVID-19 disease [38–41]. One study of community dwelling older adults in the United Kingdom found that neurodegenerative diseases were more strongly associated with COVID-19-related death than the other health conditions and demographic variables they tracked. The odds ratio of dying specifically from COVID-19 in Alzheimer disease was 2.766 and for all-cause dementia it was 2.172 compared to those without neurodegenerative diseases [42]. A study in a South Korean population found a similar increased risk in patients with dementia; despite propensity score closest neighbor matching to control for other factors they found 33.6% of individuals in the dementia group died after SARS-CoV-2 infection compared to 20.2% in the no dementia group, along with a higher rate of invasive ventilatory support requirement in the dementia group [43]. The increase risk of being infected on top of a substantially higher risk of dying from COVID-19 disease is an important point of information for counseling patients and their families. These data also highlight once again the importance of ACP for this population, and in the context of COVID-19, it is particularly salient to explore the patient

or healthcare surrogate’s thoughts surrounding cardiopulmonary resuscitation. Providers should complete do not resuscitate (DNR) documentation when appropriate. In many states the National POLST (physician orders for life sustaining treatment) program form is recognized as a standard for documenting wishes regarding cardiopulmonary resuscitation [44]. This form has the added advantage of being able to designate a broad goal of medical care, with the most aggressive option of accepting all invasive treatments to live as long as possible, an intermediate option focused on lower burden treatments to maximize function, and a third option of pure comfort oriented care and avoidance of all interventions not targeted at comfort. Legally accepted advance directives for do not resuscitate orders vary by country and state which necessitates the clinician be familiar with the particular requirements of their location of practice.

Deprescribing

Despite the commonplace use of cholinesterase inhibitors and memantine for Alzheimer disease and other dementias important questions remain about the clinical effect and optimal use of these medications. The first has been the magnitude of effect, which has varied across studies but in meta-analyses has shown small improvements in measures of cognition and function for both cholinesterase inhibitors and memantine [45–47]. Conflicting evidence exists about whether donepezil may delay or reduce the risk of nursing home placement, with the DOMINO-AD study finding a reduced risk only in the first year of treatment and the AD2000 study finding no difference between donepezil and placebo in institutional placement [48, 49]. At the same time, many studies have failed to demonstrate improvement in other important outcomes like quality of life, and the majority of these studies are of relatively short duration—typically 6 months or less [45, 46]. Significant adverse effects also exist, for example cholinesterase inhibitors are associated with an adjusted hazard ratio of 1.77 for syncope and bradycardia each and a 1.49 hazard ratio for permanent pacemaker insertion [50]. In the context of low magnitude of clinical benefit, lack of data for long term use, and important adverse effects clinicians should have a standard approach to assessing opportunities to deprescribe these medications. Multiple professional organizations have released guidelines on deprescribing cholinesterase inhibitors and memantine. The American Academy of Family Physicians’ Choosing Wisely guideline recommends that if the desired effects of cholinesterase inhibitors are not perceived within about 12 weeks the medication should be discontinued [51]. A Delphi consensus survey of experts produced the recommendation that in patients meeting the four criteria of at least 65 years old with end stage irreversible pathology,

poor one year survival prognosis, severe functional or cognitive impairment, and prioritization of symptom control over preventing disease progression that memantine should be discontinued in patients with a diagnosis of moderate or severe dementia unless it has clearly improved behavioral and psychological symptoms of dementia [52]. Due to reports of discontinuation syndromes with abrupt withdrawal of these medications it is prudent to taper them off gradually [53–55]. Based on these data, clinicians should consider discussion of deprescribing with patients and their families who have been on cholinesterase inhibitors or memantine for longer than 1 year and perceived little or no benefit, particularly in patients in advanced stage of disease or who are expected to have a short prognosis. If deprescribing is agreed upon, it can be performed as a trial with gradual taper off the medication and monitoring for worsening symptoms or function. If any significant worsening is seen within weeks of tapering off then the medication may be reinitiated.

Pain Management

Burdensome symptoms are common in individuals with dementia. A study of nursing home residents with advanced dementia showed during the 18-month follow-up period that 39.1% experienced at least 5 days per month of pain [27]. In a large study of both community and institution dwelling persons over 50% of individuals with cognitive impairment reported non-cancer pain [56]. High pain levels have also been associated with depression in patients with dementia with an odds ratio of 3.54 [57]. Data suggest that patients with cognitive impairment may have more severe pain than cognitively normal controls [58]. Given the high burden of pain in patients with dementia, there have been a number of prospective studies on the outcomes of pain treatment in this population [59–63]. In a double-blind crossover design trial of 4 weeks of acetaminophen versus placebo for nursing home patients with FAST 5 or 6 (correlating to moderate-to-severe dementia), 1000 mg acetaminophen scheduled three times a day yielded significant improvements in behaviors such as media engagement, direct social interaction, and work-like activity [60]. A cluster randomized controlled trial of nursing home residents with a diagnosis of dementia and clinically relevant behavioral disturbances investigated a stepwise approach as recommended by the American Geriatrics Society (AGS) [64]. The first step in pain treatment was acetaminophen up to 3000 mg/day, the second step was oral morphine with a maximum dose of 20 mg/day, the third step was buprenorphine transdermal patch up to 10 µg/hr, and the fourth step was oral pregabalin up to 300 mg/day. The results showed a significant improvement in agitation as measured by the Cohen-Mansfield agitation inventory and neuropsychiatric inventory—nursing home version in the

intervention group and neither cognition nor activities of daily living worsened in the intervention group [62].

Management of symptoms such as pain in the dementia population remains an area requiring further development in the literature. In addition, there are substantial barriers to the accurate assessment of pain levels in patients with dementia, and clinicians should use a combination of self-report when possible and observer evaluations to more comprehensively evaluate the patient's pain level, though no single observer scale has accumulated high-quality evidence [65]. With a low likelihood of risk in step 1 of the AGS stepwise approach to pain management in older adults, it is also appropriate to have a low threshold for initiation of treatment if there is suspicion of pain by self or observer report. As needed pain medications are infrequently administered in institutionalized patients with dementia supporting the clinical practice of using a time limited duration of scheduled acetaminophen as a first step [59]. When pain is refractory to low burden initial treatments in complex patients such as those with dementia, it is appropriate to refer to specialist care in a palliative care clinic.

Caregiving and Caregiver Burden

The majority of patients with Alzheimer disease and other dementias live in the community and 26% of those individuals live alone [66]. In cases where the patient lives alone and has not identified a caregiver, it is crucial to work with them to identify a care partner not only to provide collateral history, but also to help navigate the path of functional deterioration and escalating dependence. In cases where the patient remains capacitated, the provider may have to counsel the patient and encourage them to take these steps while also balancing respect for their autonomy and following HIPAA privacy laws. If the patient is incapacitated then the provider has the responsibility to discuss the matter at hand with their legal proxy or surrogate for healthcare decisions, following state proxy law hierarchy if no individual is nominated by the patient. At the same time, providing care to people with dementia is associated with a high degree of burden with a combination of physical, emotional, and financial hardship [67]. Care typical falls to an informal caregiver such as a relative. In the USA, this is the case for 83% of caregivers for patients with probable dementia [68]. The AARP found that Alzheimer disease or dementia was the third most common main problem or illness in the recipient of care reported by caregivers in their 2020 report [69]. In a systematic literature review of patient characteristics increasing severity of dementia, presence of frontotemporal dementia, and longer duration of illness were associated with greater caregiving burden [70]. Interventions found to improve caregiver burden include training the caregiver to adopt a more

clinical belief set about their role and other training programs focused around education, stress management, and coping skills. Evidence indicates that multiple component interventions are more effective than single interventions targeted at reducing caregiver burden [71]. A comprehensive approach to caring for people with dementia also includes viewing their caregiver(s) as part of the unit receiving care and supporting them with programs including training for behavior management, support groups, educational programs, and referral to community based organizations such as adult day care [72]. Additional research is required to develop highly effective programs to reduce caregiver burden that can be broadly implemented.

Conclusions

Palliative care is a key component to high quality care for patients with dementia and most of this care is primary palliative care from the clinician managing their neurological disease. The clinician is faced with complex communication and counseling challenges starting with rendering a diagnosis. This is almost always done in the face of considerable diagnostic uncertainty in neurodegenerative diseases. A structured approach to breaking bad news such as the SPIKES model allows providers to systematically organize these conversations. Aside from appropriate organization, clinicians should expect emotion and respond with empathy during these difficult discussions. While we may diagnose innumerable patients with Alzheimer disease through the course of our careers each time may be the only time that patient and family experience this bad news. Providers for individuals with cognitive decline should incorporate ACP as a regular component of their counseling and consider reviewing ACP at the time of diagnosis, with any major change in health state, or with any change in living arrangement. Throughout these evaluations, the clinician has to be attentive to deficiencies in the patient's capacity to make their own medical decisions and rigorously assess capacity in cases where there is uncertainty to balance the imperative of respecting autonomy while also protecting patients from the harm of treatments that do not align with their goals of care. High-quality prognostication and effective communication of these expectations serve as foundations for appropriate medical decisions. When patients have reached an advanced stage of illness they may be eligible for hospice support. If the hospice philosophy of care aligns well with their preferences, the provider should err on the side of early referral given the high degree of prognostic uncertainty in dementia. COVID-19 presents a major additional threat to individuals with dementia and redoubles the importance of addressing the patient and family's views on cardiopulmonary resuscitation as one crucial form of ACP. These wishes

should be documented on a formal advance directive whenever possible. Regarding pharmacological palliative care for patients with dementia, there remains considerable uncertainty about the long term benefits of cholinesterase inhibitors and memantine. A routine approach to deprescribing conversations with the patient and family aids in avoiding polypharmacy. Meanwhile, pain is a high burden symptom for older adults, including those with dementia. This remains an area of great need in research, however evidence supports regular evaluation of pain in patients with dementia and initiation of a step-wise approach to pain management. Effective pain control may improve behavioral and psychological symptoms of dementia as an additional benefit. The responsibility of caring for people with dementia typically falls to relatives, and the burden of that care is especially high as dementia severity progresses and for certain diseases such as frontotemporal dementia. Evaluation of caregiver burden should be a routine part of the clinician's evaluation and referral to educational resources and community based supports can improve caregiver burden.

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Required Author Forms Disclosure forms provided by the authors are available with the online version of this article.

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