

# Advance care planning and anticipatory decision making in patients with Alzheimer disease

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**Abstract:** *Early advance care planning and anticipatory decision making in the Alzheimer disease (AD) trajectory is a strategy NPs can incorporate to improve managing uncertainty around common decisions. This article explores decisions patients and caregivers face along the AD trajectory and provides resources for patients, caregivers, and NPs.*

**Keywords:** advance care planning, Alzheimer disease, anticipatory decision making, cognitive impairment, dementia, disease trajectory

**A**lzheimer disease (AD) is a complex and progressive disease. Currently, 1 in 10 individuals in the United States over age 65 have some degree of Alzheimer dementia, and there are approximately 200,000 individuals younger than age 65 with early-onset AD.<sup>1</sup> AD is individualized and variable in its presentation from the initial appearance of symptoms and throughout its progression. After diagnosis, the average survival is 4 to 8 years, although some patients may live up to 20 years.<sup>1</sup>

Patients and caregivers are challenged to make decisions about care management from the time of the

initial diagnosis throughout the disease's trajectory.<sup>2</sup> Decision making is challenging and often ambiguous, causing uncertainty for both patients and caregivers. NPs continue to fill the primary care needs of a growing U.S. population. However, it has been reported that 30% of NPs do not assess for brain health in their patients, often due to a lack of standardized protocols and assessment tools.<sup>3</sup>

Awareness and knowledge of brain health and the trajectory of AD are important for NPs to assist patients in decision making. The purpose of this article is to identify common decisions patients and caregivers experience along the AD trajectory and to explore how NPs can help patients and caregivers prepare for decisions through advance care planning (ACP) and anticipatory decision making.

### ■ AD Trajectory

The main changes in AD are observed in the presence of neurofibrillary tangles, amyloid plaques, and cerebrocortical atrophy.<sup>4</sup> Delving into the pathophysiology of AD and the complex array of brain changes is beyond the scope of this article. The National Institute on Aging and the Alzheimer's Association published updated guidelines for the diagnostic criteria of AD in 2011.<sup>5,6</sup> The diagnostic criteria were revised to incorporate scientific knowledge (including biomarkers of the underlying disease) and to address the needs of researchers and clinicians. The diagnostic criteria include three phases of AD: the preclinical phase, mild cognitive impairment, and AD dementia.<sup>5,6</sup>

For patients older than age 65, it is recommended that NPs assess and document cognitive status at the annual wellness visit so that cognitive decline can be

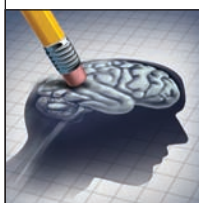
A positive screen should prompt a referral for a full dementia evaluation. There is currently insufficient evidence to recommend formal screening for early-onset AD in patients younger than age 65 or in asymptomatic patients over age 65.<sup>8</sup> However, any cognitive concerns from the patient, family, or provider should prompt further evaluation, as early diagnosis of AD is important to allow time for decision making early in AD's trajectory.

The AD trajectory is described as a transition process that progresses over three stages: early stage (mild AD), middle stage (moderate AD), and late stage (severe AD).<sup>9-11</sup> Cognitive decline is the primary clinical manifestation of AD, initiating its progression years before the first observations of dementia.<sup>12</sup>

Cognitive decline manifests at varying rates among individuals and is characterized by impairment with "memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment."<sup>11,13</sup> Signs frequently begin with forgetfulness and difficulty learning new information and progress to confusion, difficulty with organization and planning, and lack of judgment. These cognitive impairments affect the individual's ability to function independently and carry out activities of daily living.<sup>14</sup>

Patients with AD may exhibit difficulties with activities such as self-management of medications, dressing, shopping, preparing food, telephone use, navigating transportation, and financial management. Behavioral symptoms manifest with the progression of AD and exhibit as agitation, aggression, delusions, hallucinations, and wandering.<sup>15-17</sup> These changes affect the quality of life of the individual with AD and also result in caregiver stress, role strain, and caregiver burden.<sup>10,11</sup>

The AD trajectory is medically complex, unpredictable, and ambiguous, ultimately creating a future



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recognized over time.<sup>7</sup> This assessment should begin with a conversation with the patient and/or caregivers related to any concerns with confusion, memory loss, or any difficulty in performing activities of daily living or instrumental activities of daily living. Any concerns should prompt a structured cognitive assessment, such as the Mini-Cog, the General Practitioner Assessment of Cognition, or Memory Impairment Screen.<sup>7</sup>

of decisions that involve uncertainties. Uncertainty occurs when an individual is unable to derive meaning from AD-related events because of unfamiliarity with the circumstances and a lack of reference from which to adequately categorize the details related to new situations and experiences.<sup>18</sup> Patients and caregivers who are aware of the potential decisions they may encounter can prepare for challenges through anticipatory

decision making, thereby managing the uncertainties of AD.

### ■ Anticipatory decision making in AD

Decisions vary across the AD trajectory according to patients' and caregivers' physical, mental, emotional, and financial needs, values, and preferences. Much of the scientific literature focuses on the patient's, caregiver's, or healthcare provider's involvement in decision making with limited information describing the types of decisions faced along the trajectory. Many decisions concern the nuances of daily activities, whereas others are major and correspond to a patient's progression from one stage of AD to another.

Specifically, decisions are made related to: functional, cognitive, and behavioral decline; driving performance and driving safety; ACP, advance directives, end-of-life (EOL) care, palliative care, and informed consent; preparing for emergencies such as natural disasters or the death of a caregiver; medical treatments and participation in clinical trials; financial management; cost consideration; living arrangements, such as assistive living and long-term care placement, including hospice; and self-help programs for caregivers.<sup>19-41</sup>

Patients with early-onset AD may have additional decisions to make related to family, work, finances, and long-term care. Again, the literature is sparse and mainly anecdotal regarding decisions specific to the patient with early-onset AD. The Alzheimer's Association provides a list of topics and resources to consider when making decisions related to parenting, financial planning (such as saving for a child's college education), retirement planning, loss of income, and genetic testing.<sup>42,43</sup>

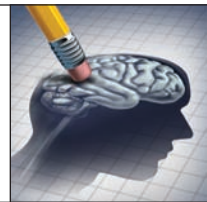
Being aware of the potential decisions the patient and caregiver may face provides NPs with the ability to facilitate discussions and anticipatory decision making early in the disease trajectory. Anticipatory decision making, therefore, is preparatory work that informs, supports, and guides patients with AD and their caregivers to manage uncertainties.<sup>44,45</sup> The goal of anticipatory decision making is to make decisions that are well thought out at a time when the patient is able to participate in decision making and make personal preferences known. Too often this does not

occur, resulting in hasty decisions that may cause patient distress and caregiver guilt.

An early and timely diagnosis prior to significant cognitive decline presents the NP with both challenges and opportunities. Early awareness and readiness to accept the diagnosis facilitates the patient's ability to participate in anticipatory decision making and express preferences regarding current and future decisions. Early diagnosis also offers patients and their caregivers the opportunity to express fears and concerns while providing the opportunity to seek out support and develop coping strategies.<sup>46</sup>

Hamann and colleagues identified that patients with early-stage AD preferred to remain autonomous when making decisions, with their caregivers maintaining a minimal role.<sup>47</sup> Hamann and colleagues also found that both providers and caregivers had a poor

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degree of understanding of the patient's desire to participate in decision making.<sup>47</sup> Therefore, it is important to elucidate patients' preferences for participation in decision making and not dismiss their choices. Engaging patients earlier in the AD trajectory is vital to maintaining autonomy as cognitive decline progresses.

The patient-provider relationship is the context within which anticipatory decision making takes place. NPs begin their work during the assessment, which provides the opportunity to identify the individual's ideas, values, and preference regarding participation in decision making. The assessment also provides the NP with the time to uncover what the patient and caregiver understand about the diagnosis.

The NP may find that the patient and caregiver do not fully comprehend what AD is or the trajectory of the disease. The NP takes the assessment information and provides education, considering the patient and caregiver's readiness, which will expand the patient's and caregiver's knowledge. In the event that the patient and caregiver are not ready, comfort, support, guidance, and counseling strategies may be initiated, leading the patient and caregiver to acceptance of the AD diagnosis.<sup>29</sup>

### ■ ACP: A strategy for anticipatory decision making

ACP is the process of understanding a patient's preferences, values, and goals of care and entrusting the decisions to uphold these goals to a trusted caregiver in the event the patient is unable to independently make decisions.<sup>48</sup> NPs use ACP as they work with patients and caregivers to contemplate, communicate, and develop a flexible plan of action for anticipatory decision making. Using ACP to anticipate potential decisions prepares the patient and caregiver, thereby managing or preventing uncertainty.<sup>49</sup>

ACP has been shown to have a positive impact on a patient's quality of life while maintaining autonomy and a sense of independence.<sup>29</sup> The importance of sharing in decisions is challenging from the perspective of the decisional capacity of the patient with AD.<sup>47,50-52</sup> Participation of patients with AD in decision making has been described to progress on a continuum. Early in the disease trajectory there is "collaborative support" in decision making between patients and caregivers.<sup>19</sup>

During early-stage AD, patients are aware of their cognitive decline but remain able to specify long-held preferences and engage in decision making while collaborating with caregivers. In mid-stage AD (where

Denning and colleagues stressed the importance of ACP prior to the point when cognitive decline interferes with decisional capacity; however, the exact point in time is specific to the patient's individual circumstances.<sup>50</sup>

Despite the documented evidence that ACP is best initiated early in the AD trajectory, there is often reluctance from the patient, caregiver, and/or provider to do so, which frequently leads to the patient being excluded, uninformed, or if the patient is informed, having a decision acted upon regardless of personal preferences.<sup>56</sup> The latter may occur when the patient did not make his or her wishes known to the caregiver or the caregiver enacted an alternative decision based on current circumstances. NPs assess the patient and caregiver's readiness to participate in ACP. ACP discussions are challenging at best, and emotions that the patient and caregivers experience include guilt, loss, and fear, which can be overwhelming.<sup>33,39</sup>

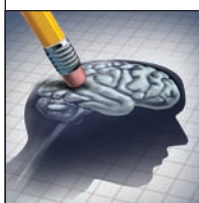
Tension and conflicts may also arise as the future trajectory is visualized.<sup>57</sup> A lack of knowledge and misperceptions are barriers to implementing ACP as a strategy for anticipatory decision making.<sup>29</sup> Educa-

tion involves a discussion on what ACP encompasses and how the strategy of ACP is an opportunity for conversations involving anticipatory decision making to maintain respect for the patient's wishes and autonomy. This time also offers an

opportunity for the patient and caregiver to express fears and concerns, giving them a chance to seek out support and develop coping strategies.<sup>46</sup> Goals of care and decisions may change over time, necessitating the need for ongoing conversations and updated documentation.

ACP provides the opportunity for the NP, patient, and caregiver to discuss and anticipate decisions. Anticipatory decision making provides a potential structure that assists the patient and caregiver in managing potential uncertainty. A multiplicity of resources will be necessary to assist patients in their anticipatory decision making (see *Anticipatory decisions in AD and associated resources*).

Relationship building, assessment, education, support, guidance, and counseling take time, consistency, and continuity. NPs must advocate for organizational policies and practice models that facilitate this continuity



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cognitive decline progresses), the caregiver's awareness of the patient's deficits supersedes that of the patient's. During this "transition period," the caregivers become more involved in the patient's choices due to a decline in the patient's perception of his or her own abilities.<sup>19</sup> Finally, in late-stage AD, the caregiver enters a period of "unilateral support" by becoming a surrogate decision maker by engaging in roles that are more "assistive" in nature (through active engagement and guidance of the patient) or "restrictive" (by prohibiting certain activities) in order to reduce harm.<sup>19</sup>

ACP is frequently addressed later in the disease trajectory with a focus on topics such as advance directives, EOL decisions, initiation of treatments, decisions about patient participation in clinical trials, and driving.<sup>33,53,54</sup> A systematic review by Robinson and colleagues suggested limited effectiveness of ACP as an intervention strategy in later stages of a disease.<sup>55</sup>



## Anticipatory decisions in AD and associated resources

Anticipatory decisions	Description of anticipatory decision	Resources
Functional decline	Alterations in the patient's ability to carry out activities of daily living and instrumental activities of daily living.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Association:</b> Information on home safety <a href="http://www.alz.org/care/alzheimers-dementia-home-safety.asp">www.alz.org/care/alzheimers-dementia-home-safety.asp</a></li> <li>• <b>National Institute on Aging:</b> Home safety and Alzheimer disease <a href="http://www.nia.nih.gov/health/home-safety-and-alzheimers-disease">www.nia.nih.gov/health/home-safety-and-alzheimers-disease</a></li> <li>• <b>Alzheimer's Foundation of America:</b>* Educational programs for healthcare providers <a href="https://alzfdn.org/professional-training-and-education">https://alzfdn.org/professional-training-and-education</a></li> <li>• <b>National Institute on Aging-Alzheimer's and Dementia Resources for Professionals:</b>* Education and assessment tools and other resources to incorporate into practice <a href="http://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals">www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals</a></li> </ul>
Cognitive decline	Alterations in attention, memory and learning, compromised judgment, and language deficits lead to a lack of competency in decision making about health or personal matters, including finances and safety matters.	<ul style="list-style-type: none"> <li>• <b>MedicAlert and Alzheimer's Association Safe Return:</b> Emergency response service for individuals with AD who wander or have a medical emergency <a href="https://www.alz.org/care/dementia-medic-alert-safe-return.asp">https://www.alz.org/care/dementia-medic-alert-safe-return.asp</a></li> <li>• <b>American Association of Retired Persons:</b> Activities for individuals with AD <a href="https://assets.aarp.org/external_sites/caregiving/homeCare/engaging_activities.html">https://assets.aarp.org/external_sites/caregiving/homeCare/engaging_activities.html</a></li> <li>• <b>Alzheimer's Society of Canada:</b> Brain booster activities <a href="http://www.alzheimer.ca/en/Home/Living-with-dementia/BrainBooster">www.alzheimer.ca/en/Home/Living-with-dementia/BrainBooster</a></li> <li>• <b>Alzheimer's Association Blog:</b> Music therapy <a href="http://blog.alz.org/caregivers-take-note-music-as-therapy">blog.alz.org/caregivers-take-note-music-as-therapy</a></li> <li>• <b>Alzheimer's Association Cognitive Impairment Care Planning Tool Kit:</b>* Assessment tools for NPs including the Mini-Cog, Katz Index of Independence in Activities of Daily, and Decision-Making Capacity Assessment <a href="http://www.alz.org/careplanning/downloads/care-planning-toolkit.pdf">www.alz.org/careplanning/downloads/care-planning-toolkit.pdf</a></li> </ul>
Behavioral decline	Alterations in behavior, such as refusal to eat and drink, or aggression create distress for the patient and caregiver.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Association:</b> Information on the management of behaviors such as anger, anxiety, depression, confusion, sleep, and sun downing <a href="http://www.alz.org/care/alzheimers-dementia-stages-behaviors.asp">www.alz.org/care/alzheimers-dementia-stages-behaviors.asp</a></li> <li>• <b>Alzheimer's Association:</b> Information on treatments for behavioral changes <a href="http://www.alz.org/alzheimers_disease_treatments_for_behavior.asp">www.alz.org/alzheimers_disease_treatments_for_behavior.asp</a></li> <li>• <b>Alzheimer's Society of British Columbia:</b> Dementia and Wandering Information Kit <a href="http://www.alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/wandering/wandering-information-kit-aug-2015.pdf">http://www.alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/wandering/wandering-information-kit-aug-2015.pdf</a></li> </ul>
Driving performance and safety	Alterations in cognitive functioning, slower reaction times, and memory issues raise questions about driver competence.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Association:</b> Dementia driving and resource center <a href="http://www.alz.org/care/alzheimers-dementia-and-driving.asp">www.alz.org/care/alzheimers-dementia-and-driving.asp</a></li> <li>• <b>National Institute on Aging:</b> Information on driving and safety <a href="http://www.nia.nih.gov/health/driving-safety-and-alzheimers-disease">www.nia.nih.gov/health/driving-safety-and-alzheimers-disease</a></li> <li>• <b>Governors Highway Safety Association:</b> Information pertaining to mature drivers <a href="http://www.ghsa.org/issues/mature-drivers">www.ghsa.org/issues/mature-drivers</a></li> <li>• <b>Family Caregiver Alliance National Center on Caregiving:</b> Information on dementia and driving <a href="http://www.caregiver.org/dementia-driving">www.caregiver.org/dementia-driving</a></li> <li>• <b>Ott BR:</b>* Assessing and modifying risks for older drivers [Internet]. Medscape. 2014. Available from: <a href="http://www.medscape.org/viewarticle/833915">www.medscape.org/viewarticle/833915</a></li> </ul>
Preparing for emergencies	Emergency management and disaster preparedness plan development, review, and reevaluation over the AD trajectory.	<ul style="list-style-type: none"> <li>• <b>CDC:</b> Resources for emergency preparedness for older adults and their caregivers <a href="http://www.cdc.gov/aging/emergency/preparedness.htm">www.cdc.gov/aging/emergency/preparedness.htm</a></li> <li>• <b>Alzheimer's Associations:</b> Making an emergency plan <a href="http://www.alz.org/care/alzheimers-dementia-disaster-preparedness.asp#help">www.alz.org/care/alzheimers-dementia-disaster-preparedness.asp#help</a></li> <li>• <b>Alzheimer's Association:</b> Links to a diverse array of state and local resources for disaster preparedness and planning as well as best practices for healthcare providers. <a href="http://www.alz.org/documents_custom/public-health/spotlight-disaster.pdf">www.alz.org/documents_custom/public-health/spotlight-disaster.pdf</a></li> <li>• <b>The Hartford:</b> Resource for disaster planning and emergency caregiving <a href="http://www.hartfordauto.thehartford.com/UI/Downloads/CalmBeforeStormBro.pdf">www.hartfordauto.thehartford.com/UI/Downloads/CalmBeforeStormBro.pdf</a></li> <li>• <b>CDC:</b>* NPs who wish to enhance their knowledge and skills in this area may access these training resources: <a href="http://www.cdc.gov/aging/emergency/training.htm">www.cdc.gov/aging/emergency/training.htm</a></li> </ul>

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### Anticipatory decisions in AD and associated resources (Continued)

Anticipatory decisions	Description of anticipatory decision	Resources
Treatments and participation in clinical trials	Pharmacologic and nonpharmacologic treatments to help improve or slow down AD progression.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Association:</b> Medication safety <a href="http://www.alz.org/care/dementia-medication-drug-safety.asp">www.alz.org/care/dementia-medication-drug-safety.asp</a></li> <li>• <b>National Institute on Aging:</b> Directory of AD research centers <a href="http://www.nia.nih.gov/health/alzheimers-disease-research-centers">www.nia.nih.gov/health/alzheimers-disease-research-centers</a></li> <li>• <b>Alzheimer's Association:</b> Resources for ongoing AD research and clinical trials <a href="http://www.alz.org/research/overview.asp">www.alz.org/research/overview.asp</a></li> <li>• <b>National Society of Genetic Counselors:</b> Find a genetic counselor to determine if genetic testing may be helpful for future family decision making <a href="http://www.nsgc.org/findageneticcounselor">www.nsgc.org/findageneticcounselor</a></li> <li>• <b>The Hartford Institute for Geriatric Nursing:</b>* Opportunities for NPs to enhance their knowledge and skills in the specialization of older adult care including those with AD. <a href="http://www.consultgeri.org">www.consultgeri.org</a></li> </ul>
Living arrangements	AD progression introduces changes in living arrangements including: bringing additional help into the home, respite, assistive living, adult day care, home care, and long-term care.	<p>Information on living arrangements and types of care are provided by the Alzheimer's Association:</p> <ul style="list-style-type: none"> <li>• <b>Adult day care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-adult-day-centers.asp">www.alz.org/care/alzheimers-dementia-adult-day-centers.asp</a></li> <li>• <b>Home care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-in-home-health.asp">www.alz.org/care/alzheimers-dementia-in-home-health.asp</a></li> <li>• <b>Residential care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-residential-facilities.asp">www.alz.org/care/alzheimers-dementia-residential-facilities.asp</a></li> <li>• <b>Respite care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp">www.alz.org/care/alzheimers-dementia-caregiver-respite.asp</a></li> <li>• <b>Hospice care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-hospice.asp">www.alz.org/care/alzheimers-dementia-hospice.asp</a></li> </ul>
Caregiver support	Programs provide support for caregivers in daily decisions including education, problem-solving resources, social support, and programs to educate the caregiver on financial resources.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Navigator:</b> Helps lead patients and caregivers to answers by generating personalized action plans as well as assistance with local resources <a href="http://www.alzheimersnavigator.org">www.alzheimersnavigator.org</a></li> <li>• <b>Alzheimer's Foundation of America:</b> Caregiver support group <a href="http://www.alzfdn.org/caregiving-resources/2860-2">www.alzfdn.org/caregiving-resources/2860-2</a></li> <li>• <b>ALZ Connected:</b> A free online community forum <a href="http://www.alzconnected.org">www.alzconnected.org</a></li> <li>• <b>Community resource locator:</b> Includes Alzheimer Association programs, housing options, and medical and community services <a href="http://www.communityresourcefinder.org">www.communityresourcefinder.org</a></li> <li>• <b>Care Training Resource:</b> Seminars, e-learning courses, DVDs, and books to help the caregiver with caregiving and coping skills <a href="https://www.alz.org/care/alzheimers-dementia-care-training-certification.asp">https://www.alz.org/care/alzheimers-dementia-care-training-certification.asp</a></li> <li>• <b>HELPGUIDE.ORG:</b> Tips of AD caregivers including identifying and managing burnout <a href="http://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm">www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm</a></li> <li>• <b>Alzheimer's Association:</b> Information on apps for caregivers <a href="http://www.alzheimersblog.org/2018/03/30/activity-apps/">www.alzheimersblog.org/2018/03/30/activity-apps/</a></li> </ul>
Financial management and cost considerations of care	Financial management skills decline early in the AD trajectory necessitating financial planning. In addition, costly programs and treatments may not be covered by insurance, creating a barrier to needed resources.	<ul style="list-style-type: none"> <li>• <b>Alzheimer's Association:</b> Financial planning resources: <a href="http://www.alz.org/i-have-alz/financial-planning.asp">www.alz.org/i-have-alz/financial-planning.asp</a></li> </ul> <p>Additional information is offered by the Alzheimer's Association in the area of financial management and cost of providing care at:</p> <ul style="list-style-type: none"> <li>• <b>Legal planning in the area of financial management and cost of care:</b> <a href="http://www.alz.org/i-have-alz/legal-planning.asp">www.alz.org/i-have-alz/legal-planning.asp</a></li> <li>• <b>Planning for cost of care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-common-costs.asp">www.alz.org/care/alzheimers-dementia-common-costs.asp</a></li> <li>• <b>Paying for care:</b> <a href="http://www.alz.org/care/alzheimers-dementia-costs-paying-for-care.asp">www.alz.org/care/alzheimers-dementia-costs-paying-for-care.asp</a></li> <li>• <b>Medicare:</b> <a href="http://www.alz.org/care/alzheimers-dementia-medicare.asp">www.alz.org/care/alzheimers-dementia-medicare.asp</a></li> <li>• <b>Medicaid:</b> <a href="http://www.alz.org/care/alzheimers-dementia-medicaid.asp">www.alz.org/care/alzheimers-dementia-medicaid.asp</a></li> </ul>

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**Anticipatory decisions in AD and associated resources (Continued)**

Anticipatory decisions	Description of anticipatory decision	Resources
ACP, advance directives, end-of-life palliative care, hospice, and MOLST	These resources can assist in anticipatory decision making about healthcare proxies, advance directives (cardiopulmonary resuscitation, hospitalization, I.V. medication, hydration, and nutrition); end-of-life care, hospice, palliative care, and MOLST.	<ul style="list-style-type: none"> <li>• <b>CDC:</b> ACP patient information <a href="http://www.cdc.gov/aging/advancecareplanning/index.htm">www.cdc.gov/aging/advancecareplanning/index.htm</a></li> <li>• <b>National Institute on Aging:</b> Advance care planning patient information <a href="http://www.nia.nih.gov/health/caregiving/advance-care-planning">www.nia.nih.gov/health/caregiving/advance-care-planning</a></li> <li>• <b>Compassion and Support at End of Life:</b> Information on ACP, MOLST, palliative care, pain management, and hospice <a href="http://www.compassionandsupport.org">www.compassionandsupport.org</a></li> <li>• <b>Medical Orders for Life-Sustaining Treatment (MOLST):*</b> Information for professionals <a href="http://www.compassionandsupport.org/index.php/for_professionals/molst/molst_form">www.compassionandsupport.org/index.php/for_professionals/molst/molst_form</a></li> <li>• <b>CDC:*</b> Course on ACP for healthcare professionals <a href="http://www.cdc.gov/aging/advancecareplanning/care-planning-course.htm">www.cdc.gov/aging/advancecareplanning/care-planning-course.htm</a></li> </ul>
Early-onset AD	These resources can assist in anticipatory decision making for the unique decisions a patient with early-onset AD may face, including family planning and legal and financial planning.	<ul style="list-style-type: none"> <li>• <b>National Institute on Aging:</b> Early-onset AD resource list <a href="http://www.nia.nih.gov/health/early-onset-alzheimers-disease-resource-list">www.nia.nih.gov/health/early-onset-alzheimers-disease-resource-list</a></li> <li>• <b>Alzheimer's Association:</b> Younger-onset Alzheimer's resources <a href="http://www.alz.org/national/documents/brochure_youngeronsset.pdf">www.alz.org/national/documents/brochure_youngeronsset.pdf</a></li> </ul>

\* Indicates resources specific for NPs


and consistency to reduce patient uncertainty.<sup>33</sup> Since January 2016, the Centers for Medicare and Medicaid Services (CMS) reimburses for ACP.<sup>58</sup> In addition to discussions about advance directives, discussions about patient preferences and treatments that may occur after the decline of independent decision-making abilities are also eligible for reimbursement.

The Current Procedural Terminology (CPT) code 99497 is used for the first 30 minutes of face-to-face discussion with the patient and/or caregiver, and CPT 99498 is used for each additional 30 minutes. In January 2017, CMS approved CPT code G0505 for the creation of a comprehensive care plan, including cognitive, functional, and safety assessments; an assessment of caregiver needs; and ACP discussions.<sup>59</sup>

### Conclusion

AD is a global public health issue that requires heightened awareness, advocacy, accurate and timely diagnosis, quality ongoing care, accessible and acceptable services and networks, caregiver support, ongoing research, and a workforce with essential knowledge and skill sets.<sup>11</sup> Today, AD is diagnosed

earlier than previous decades, offering opportunities for patients and caregivers to visualize their potential disease trajectory and offering a time for contemplation, discussion, and anticipatory decision making that is mindful of individual preferences and choices.

The initiation of ACP that includes anticipatory decision making for common decisions patients and caregivers face along the AD trajectory is an opportunity for the NP to advocate for this population by raising their awareness about ACP, providing education, counseling, support, and guidance during the ACP process, thereby addressing AD as the public health issue expressed by the World Health Organization.<sup>11</sup> 

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