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Nevada Task Force on Alzheimer's Disease

Proposed New Recommendation (11-15-22)

TFAD Member Work Group: Gini Cunningham, Susan Hirsch (lead), Chuck McClatchey, Dr. Dylan Wint
Requested Review: Jennifer Richards
Proposed title for recommendation area: Advance Care Planning

Justification:
Advance care planning is considered to be a significant unmet need for persons living with dementia. *Advance Care Planning* refers to a process where an individual documents their wishes for care through advance directives and designates someone who can make decisions on their behalf if the individual does not have the capacity to do so. *Advance Directives* are legal and medical documents stating a person's wishes for their future care. Examples are Health Care Power of Attorney, Declaration (Living Will) and Do Not Resuscitate Order. Without advance directives in place, an individual's wishes for their care may not be followed and under some circumstances, a guardian may be appointed to make all health care decisions on behalf of the individual. Without data specific to individuals living with dementia, estimates are about half of all those 65+ have completed at least one advance directive, illustrating the scope of unmet need.

As advance directives must be completed when an individual is deemed to have decision-making capacity, there is a heightened sense of urgency for those who are living with dementia due to changes in cognitive capacity over time. The concept of capacity refers to an individual's ability to make a particular decision at a specific point in time. All adults are presumed to have decision-making capacity. A person with impaired capacity may still have the ability to make decisions related to their advance directives. A capacity assessment completed by a physician can determine whether a person living with dementia has the ability to make a specific decision at that time such as the appointment of a health care power of attorney. The evaluation of decision-making capacity assesses whether an individual is able to demonstrate understanding, appreciation and reasoning related to their decision as well as communicate a consistent choice. Advance Directives go into effect when an individual is evaluated to no longer have capacity to make the decisions specified in each completed document.

Individuals living with dementia do not complete advance directives due a range of factors. Feedback from individuals, care partners and professionals provide insights into commonly

experienced challenges and obstacles including lack of knowledge, access to resources and misconceptions/misinformation. Many are not aware of the potential benefits of advance care planning or resultant legal processes such as guardianship that can occur if there are no documented wishes. The process of completing advance directives can seem daunting and may be costly. Some are undecided about their future health care wishes; others worry about placing a burden on the person designated as their power of attorney or have no one willing to serve in this capacity. Misconceptions about when documents go into effect lead to concerns about loss of independence once a surrogate decision-maker has been selected. There is apprehension that, once documented, wishes will not be followed. In some instances, an individual living with dementia may be required to obtain a certification of competency prior to being able to fully execute their advance directives. Education about advance care planning is fundamental to address the myriad of obstacles individuals encounter engaging in this process and completing the advance directives of their choice.

In a 2016 Civil Legal Needs Study and Economic Impact Assessment, the Nevada Supreme Court Access to Justice Commission found that nearly 76% of civil legal needs in the state go unmet. However, investment in community legal services yields a return on investment of 7:1. Nevada legal services providers offering assistance with advance directives has yielded a savings of $18M statewide. Therefore, access to advance directives is an “access to justice” issue for Nevada’s citizens.

Health care and legal professionals supporting individuals living with dementia can benefit from education and training about advance care planning focused on such pertinent topics as decision-making capacity for completion of advance directives and when documents such as the health care power of attorney go into effect. Education/training can help facilitate discussions with patients/clients about the benefits of advance care planning and referrals to community resources for assistance.

Recommendation:
Advance Care Planning is a process where an individual documents their wishes for care and designates someone who can make decisions on their behalf if the individual does not have the capacity to do so. Advance Care Planning is especially important for persons living with dementia as their decision-making capacity is likely to be diminished over time. TFAD requests ADSD’s assistance in promoting educational/training resources to individuals living with dementia, care partners and professionals (e.g., medical, legal) to support persons living with dementia complete their advance care planning documents.

Below are potential opportunities that could be implemented and/or expanded:

- **Support for individuals living with dementia and care partners**
    - Promote awareness and distribution of Nevada's dementia-specific advance care planning documents/instructions through senior law and community service providers:
        - Engage with education initiatives such as the Legal Aid Library Kiosk project to distribute an easy-to-understand explanation of advance care planning, list of resources and Nevada forms/instructions
        - Encourage Nevada Care Connection Resource Center's Resource Navigators to assess individual needs for advance care planning and refer to legal services providers
        - Encourage Nevada's senior law providers to identify effective approaches to facilitate completion of advance care planning for clients living with dementia
    - Explore opportunities to work with hospitals and healthcare providers to include community resources for assistance completing advance directives as part of the advance planning information distributed to individuals
    - Explore potential of convening stakeholders across relevant disciplines along with participation by individuals living with dementia and care partners to identify specific efforts/collaborations to promote advance care planning

- **Options for professional education/training** (legal, health care, financial)
    - Encourage and support stakeholders including but not limited to ADSD, State Bar of Nevada, Nevada Supreme Court Access to Justice Commission, UNLV Boyd School of Law, legal services providers, Volunteer Attorneys for Rural Nevadans (VARN) along with health care specialists to offer continuing education/training curricula for professionals and students about advance care planning for individuals living with dementia
    - Promote the creation of a state-level clearinghouse for advance care planning information including but not limited to educational materials, Nevada-specific forms, community resources, legal services providers and relevant health care providers
    - Explore opportunities to create medical/legal collaborations to address issues related to the determination of capacity for persons living with dementia

Indicators:

- Receive updates from ADSD on various advance care planning topics including but not limited to community education initiatives, engagement with hospitals/health care providers about information targeted to patients/families, resources/education offered

under Older Americans Act (OAA) legal services grants to assist with completion of advance directives, options to create a state-level clearinghouse for Nevada-specific information, engagement with legal community regarding efforts to increase education/training options focused on individuals living with dementia

- Monitor data on advance care planning assistance provided by OAA funded legal services providers and advance care planning education/training offered by various stakeholders to include frequency, topics, participation rates and program evaluation
- Request updates from various stakeholders on feasibility of medical/legal collaborations related to advance care planning

Potential Funding:
Grants, donations and/or gifts. Specific sources may include Older Americans Act funds (through ADSD)