Revised 10/23/24

Recommendation #16: Advance Care Planning

TFAD Member Lead: Susan Hirsch

Current Recommendation as Stated:

Background/Justification:

Advance care planning is a significant unmet need for people living with dementia. Advance Care Planning refers to a process where an individual clearly documents their wishes for care through advance directives and/or 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 'Healthcare Power of Attorney', 'Declaration (Living Will)' and 'Do Not Resuscitate (DNR) 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 healthcare decisions on behalf of the individual. Without data specific to people living with dementia, estimates are that only 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 an impaired capacity may still have the ability to make decisions related to their advanced 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 healthcare power of attorney. The evaluation of decision-making capacity assesses whether an individual can 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. People living with dementia often do not complete advance directives due to 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 or misinformation. Many are not aware of the potential benefits of advance care planning or resultant legal processes, such as guardianship, which 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 healthcare 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, a person living with dementia may be required to obtain a certification of competency prior to being able to fully execute their advance directives. Education about advanced care planning is fundamental to addressing the myriads of obstacles individuals encounter engaging in this process and completing advanced directives according to their specific choices. 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 to 1. Nevada legal services providers assist with advanced directives have yielded savings of $18M statewide. Therefore, access to advance directives is an "access to justice" issue for Nevada citizens. Healthcare and legal professionals supporting people 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 healthcare power of attorney go into effect. Education and training can help facilitate discussions with patients and clients about the benefits of advance care planning and support referrals to community resources for assistance.

Recommendation:

TFAD encourages ADSD to develop and promote education and training resources available to people living with dementia, their care partners and professionals (e.g., medical, legal) to support people living with dementia in completing their advance care planning documents. The following are potential opportunities that could be implemented and/or expanded: 1) Support for people 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, including: o 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; o Encourage Nevada Care Connection Resource Center's Resource Navigators to assess individual needs for advance care planning and refer to legal services providers; and o 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 people living with dementia and care partners to identify specific

efforts/collaborations to promote advance care planning. 2) Options for professional education/training (legal, healthcare, 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 healthcare specialists to offer continuing education/training curricula for professionals and students about advance care planning for people 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 healthcare providers. • Explore opportunities to create medical/legal collaborations to address issues related to the determination of capacity for persons living with dementia.

Indicators:

1) Receive updates from ADSD on various advance care planning topics, including, but not limited to: • Community education initiatives; • Engagement with hospitals/healthcare 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; and • Engagement with legal community regarding efforts to increase education/training options focused on people living with dementia.
2) 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.
3) Request updates from various stakeholders on feasibility of medical/legal collaborations related to advance care planning.

Potential Funding:

- Grants, gifts and donations • Specific sources may include Older Americans Act funds (through ADSD)

Current Status:

This new recommendation was a significant area of focus during the 2023-24 review of the State Plan. Speakers representing legal services, medical services as well as ADSD provided in-depth presentations on various topics related to this recommendation.

Determination:

Revised/Updated

Justification:

As the recommendation was new for the 2023-24 State Plan, the background/justification is no longer included in this updated version. With input from TFAD members, several presentations were provided by legal and medical experts on various aspects of this topic. The proposed revisions are minimal and designed to better align this recommendation with content provided in the presentations and facilitate continued progress on 2025-26 State Plan goals.

Suggested Revisions:

Recommendation #16 Advance Care Planning

Advance Care Planning refers to a process where an individual states their wishes for future care by completing advance directive documents and designating someone who can make decisions on their behalf if the individual does not have the capacity to do so. As advanced directives must be completed when an individual is deemed to have decision-making capacity, there is heightened urgency for individuals who are living with dementia to complete their advanced directive documents. The concept of capacity refers to an individual's ability to make a particular decision at a specific point in time. A capacity assessment completed by a qualified medical professional using a recognized and generally accepted cognitive assessment can determine whether a person living with dementia has decision-making capacity to engage in advance care planning at a specific point in time. 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 reasonable and consistent choice. A person with an impaired capacity may still have the ability to make decisions related to their advanced directives. Education/training is fundamental to increasing awareness about advance care planning, specifically to individuals living with dementia and address obstacles that may be encountered throughout this process.

The following are potential opportunities for ADSD to offer leadership and coordination related to advance care planning:

- Promote awareness and distribution of Nevada's dementia-specific advance care planning documents/instructions through senior law and community service providers
- Encourage Nevada Care Connection Resource Center's Resource Navigators to assess an individual's need for advance care planning and refer to legal services providers
- Explore opportunities to work with hospitals and healthcare providers to encourage patients to have advance directives in their medical records and

electronically stored with Nevada Lockbox (administered by the Nevada Secretary of State)

- Encourage and support stakeholders, including but not limited to ADSD, State Bar of Nevada, Nevada Supreme Court Access to Justice Commission, UNLV William S. Boyd School of Law, National Judicial College, legal services providers, Volunteer Attorneys for Rural Nevadans (VARN) along with healthcare specialists, to offer continuing education/training curricula for professionals and students about advance care planning and decision-making capacity for people living with dementia
- Promote the creation of a state-level clearinghouse for advance care planning information, including Nevada-specific forms, educational materials, community resources, legal services providers and relevant healthcare providers

Indicators:

1) Receive updates from ADSD on various advance care planning topics including:
    - Resources/education offered under Older Americans Act (OAA) legal and other grants to assist individuals to complete their advance directives
    - Options to create a state-level clearinghouse for Nevada-specific information
    - Engagement with the legal community, health care professionals and other key stakeholders regarding education/training options and efforts to enhance available resources
    - Decision-making capacity issues related to the completion and execution of advance care planning documents

2) Monitor data related to advance care planning provided through OAA funded legal services providers and Nevada Care Connection Resource Centers including but not limited to training/education offered for individuals and professionals, frequency of requests for assistance, demographic data for individuals served and unmet needs identified.

3) Request updates from various community stakeholders (e.g., legal services providers/organizations/educators, health care professionals, hospitals) on advance care planning topics including education/training initiatives, decision-making capacity related to completion and execution of documents and unmet needs/barriers encountered.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include Older Americans Act funds (through ADSD)