



# Early Detection & Accurate Diagnosis

Communities are encouraged to utilize the information in the Early Detection & Accurate Diagnosis section of the toolkit to raise awareness of the benefits of early detection and diagnosis among providers and the public.





# Early Detection & Accurate Diagnosis

## Why Knowing Early Matters

### BENEFITS FOR EARLY & ACCURATE DIAGNOSIS

Dementia is the loss of cognitive functioning and behavioral abilities that is severe enough to interfere with activities of daily living. There are multiple forms of dementia including Lewy body dementia, vascular dementia, and Alzheimer's disease, the most common type of dementia. Although Alzheimer's and other dementias is not a normal part of aging, the greatest risk factor for developing Alzheimer's disease is age. There is currently no cure for Alzheimer's disease, but there are many benefits in receiving an accurate and early diagnosis. There are multiple reasons to receive an early and accurate diagnosis, both for the individual and the caregiver.

#### **ESTABLISHING CARE PARTNERS**

According to the 2016 Tennessee Subjective Cognitive Decline Behavioral Risk Factor Surveillance System (BRFSS) module, 51% of people with subjective cognitive decline had to give up day to day activities and 41% of people with subjective cognitive decline need help with household tasks. Early identification of services to support people with dementia and the caregiver can dramatically impact quality of life and the ability to age in place.

#### **ADVANCED CARE PLANNING**

Receiving an early and accurate diagnosis allows for individuals living with cognitive decline to determine their healthcare wishes with their care partners prior to the disease progressing.

#### **PREPARING FINANCIALLY**

The financial impact of a dementia diagnosis for the PWD and their caregiver is significant. Delayed or inaccurate diagnosis can contribute to high healthcare costs and lost time from work or other responsibilities. As the disease progresses, medical treatments, in home care, long-term care, medications, therapy, and personal supplies compound financial burden. PWD and caregivers must navigate housing, legal, supervision, and care assistance needs. Receiving an early and accurate diagnosis allows individuals and their caregivers to plan for the financial implications of the disease and prepare for future needs.

#### **ACCESSING SUPPORT GROUPS**

There are a multitude of support groups that exists across Tennessee for those living with Alzheimer's or other dementias and support groups for caregivers. Receiving an early diagnosis allows for the individual with a diagnosis to access support groups at early stages of the disease and for the caregiver to find support groups in their respective area. Further information about locating support groups in Tennessee can be found in the, "Caregiver Quick Guide" section of the toolkit.



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### **MANAGING COMORBIDITIES**

According to the 2016 Subjective Cognitive Decline BFRSS Module, 87% of people living with subjective cognitive decline have at least one chronic condition. Receiving an early and accurate diagnosis will allow individuals to work with their healthcare provider, caregivers, and community support members to develop a plan to manage comorbidities by promoting a healthy lifestyle and managing medications.

### **ACCESSING COMMUNITY RESOURCES**

There are a variety of community resources available to those that receive a diagnosis and their caregivers, but it can be difficult to know what resources an individual is eligible to access and receive. The section of the toolkit titled, "Caregiver Quick Guide" includes initial steps an individual should take once a diagnosis is received. It is critical that upon noticing signs of cognitive decline that an individual receive an appropriate diagnosis in order to be eligible for some of these services. Many local resources require an application process and have certain criteria for qualification; therefore, early diagnosis can help facilitate appropriate referrals prior to an urgent need being present as the disease progresses.

### **AVOIDING OR ADDRESSING POTENTIAL SAFETY ISSUES**

There many behavioral changes that can occur when someone is living with Alzheimer's disease or other dementias, such as wandering. Receiving an early and accurate diagnosis allows for caregivers to learn about the progression of the specific type of dementia their loved one may have so that if behaviors begin to occur they can respond appropriately. This also allows for individuals and their caregivers to create a safe environment for their loved ones. Later sections of the toolkit addresses social engagement for those with a diagnosis and a safe physical environment.

### **RESEARCH PARTICIPATION**

Although there is a growing body of science related to Alzheimer's and other dementias, there is still a lot about the disease that is unknown. In order to gain further understanding about causes of the disease, disease process, and potential cures for the disease, it is critical for more individuals with early stages of Alzheimer's and other dementias to participate in research opportunities. An early detection of the disease allows individuals to make decisions about participating in research and be connected with the appropriate research opportunity.



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### ENCOURAGING EARLY DETECTION & DIAGNOSIS

There are multiple barriers associated with accurate and early diagnosis including limited public awareness related to noticing the signs of cognitive impairment, lack of training for healthcare providers, lack of time during healthcare visits, and overall stigma about Alzheimer's and other dementias. To encourage early detection and diagnosis in local communities, there are a variety of strategies and action steps communities can employ. According to the 2016 Subjective Cognitive Decline BFRSS Module, less than half of Tennesseans living with subjective cognitive decline have discussed their symptoms with a healthcare provider.

#### **INCREASE PUBLIC AWARENESS**

There is a common misconception that developing Alzheimer's or other dementias is a normal part of the aging process and unavoidable; however like other chronic conditions, there is opportunity for risk reduction and managing disease progression. There are multiple ways to increase public knowledge about Alzheimer's and other dementias and to encourage early detection and accurate diagnosis.

#### **TARGET AT RISK POPULATIONS**

African Americans, Hispanics, and women are more at risk for developing cognitive decline. Communities can use a targeted approach in increasing awareness among these populations by ensuring materials and messaging are inclusive and accessible by providing messaging at locations these individuals access for goods and services. Some examples may include:

- Including information in parent packets during school registration;
- Posting information at local health clinics;
- Offering educational materials in multiple languages;
- Working with OB/GYN offices to include information in waiting areas;
- Use social media to share information (Pinterest, Instagram, SnapChat, Twitter, Facebook)

At the end of this toolkit section, you will find materials to help educate at risk populations.

#### **FAITH COMMUNITY**

Faith organizations can play an important role in encouraging early detection and diagnosis among congregation members. The section titled "Supporting Faith Leaders and Congregations" in the Dementia Friendly Toolkit offers strategies to assist congregations and faith leaders in educating congregation members about Alzheimer's disease and other dementias, encouraging early detection and diagnosis, and supporting those with the disease and their caregivers.



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### VIDEOS

The videos below highlight the benefits of early detection and diagnosis. Share these videos with the public via social media outlets, in waiting rooms at the hospital or healthcare provider, at a lunch and learn, or presentation. Videos are an easy way to educate the public about cognitive decline, warning signs, and early detection and accurate diagnosis. The videos are located in the Risk Reduction Messaging section of the toolkit.

### WARNING SIGNS

Alzheimer's disease, a type of dementia, is a progressive disease with warning signs that occur in the early stages of the disease. Educating the public about these warning signs will help individuals identify the signs early and encourage consultation with a trained healthcare provider. Documents related to the 10 warning signs are located in the Risk Reduction Messaging section of the toolkit.

## WORKING WITH HEALTHCARE PROVIDERS

A multitude of barriers are associated with receiving an early and accurate diagnosis including a lack of time, lack of dementia training among healthcare professionals, concerns about stigma, and difficulty recognizing signs and symptoms, and not understanding the benefits of providing an early and accurate diagnosis. There are several strategies community advocates can employ to encourage early detection and accurate diagnosis among healthcare providers.

### PARTNER WITH HEALTH SYSTEMS

Health systems employ hundreds, and sometimes, thousands of employees. A hospital system often hosts lunch and learns and in-services for providers related to topics that impact or improve provider practice. These settings provide an opportunity to talk about Alzheimer's and other dementias, importance of early detection and diagnosis, and community resources to support those that are experiencing cognitive decline. Large organizations such as hospital systems will often send out system-wide communication such as newsletters or emails to inform staff of important happenings. These types of communication mechanisms also offer an opportunity for inclusion of information about Alzheimer's and other dementias. Consider contacting the systems education/training coordinator to discuss opportunities to connect with healthcare providers in their respective system. Consider targeting nurses and other direct-care staff such as social workers, pastoral care, discharge planners, and physical therapists working in hospital settings to provide them with information and resources to allow them to better care for patients with dementia from admission to discharge planning.



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### COMMISSIONER'S COLLEAGUE LETTER

The Tennessee Department of Health Commissioner, Dr. Lisa Piercey, has provided a dear colleague letter for communities to utilize when working with healthcare providers, stressing the importance of addressing risk factors associated with Alzheimer's and other dementias and the benefits of early detection and diagnosis. This letter highlights the importance of early detection and diagnosis to both the Tennessee Department of Health, and those living with cognitive decline and their caregivers. The Commissioner's Dear Colleague letter can be utilized by any community working with providers in electronic or printed form and can be accessed in PDF form at the end of Early Detection and Diagnosis section of the toolkit.

### UTILIZING MEDICARE ANNUAL WELLNESS VISIT

The Medicare Annual Wellness Visit offers an opportunity for providers to conduct a cognitive screening assessment. Community advocates can work with providers to educate about evidence based practice related to cognitive assessments, community resources, and coding techniques to maximize reimbursement. At the end of this toolkit section, information from the Alzheimer's Association and the Centers for Medicare and Medicaid Services about the Medicare Annual Wellness Visit can be accessed. Further information can be found at the in the toolkit section titled, "Hospital Systems and Healthcare Providers", where information about performing a cognitive assessment, working with local hospital systems, and a provider patient resource guide can be accessed.

### ADVANCED CARE PLANNING

Communicating the importance of advanced care planning a key aspect when discussing early detection and accurate diagnosis with healthcare providers. The Honoring Choices Tennessee coalition is leading the discussion in Tennessee on the importance of conversations between healthcare providers, patients, and caregivers on completing advance directives. To equip and educate healthcare professionals with useful information for use in practice to facilitate these conversations with their patients about advance directives and answer their questions, Honoring Choices Tennessee, has developed resources and toolkits specifically designed for physicians, nurses, social workers, case managers, chaplains and other health care providers. Visit the Honoring Choices Tennessee website to access these materials and other related documents. Additional information about billing codes associated with Advanced Care Planning can be located at the end of this toolkit.

### Honoring Choices Tennessee Website:

<https://advancedirectivestn.org/healthcare-professionals>



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### PROVIDING PROVIDER RESOURCES

Some providers may be reluctant to provide a diagnosis of Alzheimer's and other dementias because of the stigma associated with the disease and the lack of treatment. It is important to stress that although there is not currently a cure, there are steps that those living with the disease and their caretakers can take to better manage the disease and plan for the future. In the toolkit section titled Provider Education & Care Consultation, there are resources that healthcare providers can utilize to facilitate early referrals to community resources post diagnosis or while awaiting referral to a specialist. These resources can also be used to inform nurses, social workers, and case managers about the resources available for these individuals.

## References & Resources

1. **Alzheimer's Association Policy Brief Early Detection and Diagnosis of Alzheimer's Dementia:**

[https://act.alz.org/site/DocServer/Policy\\_Brief\\_-\\_Early\\_Detection\\_and\\_Diagnosis\\_Brief\\_\\_Assn.pdf?docID=53576](https://act.alz.org/site/DocServer/Policy_Brief_-_Early_Detection_and_Diagnosis_Brief__Assn.pdf?docID=53576)

2. **Alzheimer's Association Cognitive Assessment and Care Planning Services: Alzheimer's Association Expert Task Force Recommendations and Tools for Implementation:** <https://www.alz.org/careplanning/downloads/cms-consensus.pdf>

3. **Centers for Disease Control and Prevention (CDC) Tennessee Subjective Cognitive Decline:**

<https://www.cdc.gov/aging/data/pdf/Tennessee-2016-Cognitive-Infographic-508.pdf>

4. **Centers for Medicare & Medicaid Services (CMS) Annual Wellness Visit:**

<https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AWV-Chart-ICN905706TextOnly.pdf>

5. **Centers for Medicare & Medicaid Services (CMS) Advance Care Planning:**

<https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>

6. **Honoring Choices TN Healthcare Providers:**

<https://advancedirectivestn.org/healthcare-professionals>



# BENEFITS OF EARLY DETECTION & ACCURATE DIAGNOSIS



## Addressing Safety Concerns

Allows the patient and caregiver to assess safety issues such as driving, wandering, and home safety.



## Research Options

Offers the patient to the option to participate in research opportunities to support expanding treatment options.



## Establishing Care Partners

Helps patients understand the need for care either with a care partner, in home support services, or long-term care.



## Advanced Care Planning

Allows for patient choice and provides families guidance as the disease progresses.



## Financial Planning

Allows the patient to determine what financial changes need to be made as increased care is needed.



## Accessing Community Resources

Patients are able to explore insurance options, care support, respite services, and local support groups.



## Managing Comorbidities

Early diagnosis provides an opportunity for chronic condition management for the patient, caregiver, and provider.

## Advanced Care Planning: CPT® codes 99497 and 99499

Medicare pays for ACP either as an optional element of a patient's Annual Wellness visit or separate Medicare Part B medically necessary service.

## Cognitive Assessment: CPT® code 99483

includes nine assessment elements including a written care plan, caregiver knowledge, and an evaluation of safety.

## Managing Chronic Conditions: CPT® code 99490

is an appropriate service to use for monthly care management of a patient with dementia plus at least one other chronic condition, after a cognitive impairment care plan has been developed and documented.