

FACULTY GUIDE

Core Module 4:

Providing and Discussing a Dementia Diagnosis with Persons Living with Dementia (PLwD) and their Care Partners

October 2018

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Slide 1:

- Module 4 addresses the benefits and challenges associated with providing a diagnosis of dementia to a person and to his/her care partners. We will examine both the clinician's and persons living with dementia's barriers to discussing the diagnosis, as well as the best practices for discussing a diagnosis with persons living with dementia and their care partner(s), all within Health Insurance Portability and Accountability Act (or HIPAA) policies.

Slide 3:

- In this module, we are going to address the benefits of providing an early diagnosis of dementia, as well as the recommendations, barriers, and challenges for providing the diagnosis.

Slide 4:

- Our goal, by the time we finish with this module, is for you to complete four learning objectives. You will be able to:
 - Identify points to address with persons who have a diagnosis of dementia.
 - Identify important issues to consider when discussing a dementia diagnosis with care partners.
 - Summarize Health Insurance Portability and Accountability Act (HIPAA) rules affecting the disclosure of a diagnosis of dementia to an individual's family members, friends, or other care partner(s) involved in the care or payment for care of persons living with dementia.
 - Describe when to refer persons living with dementia to a neurologist, geriatric psychiatrist, neuropsychologist, or a national Alzheimer's Disease Center.

Slide 6:

- Ideally, the diagnosis of dementia is provided by members of the health care team using a person-centered approach that honors PLWD's personhood, life goals and care preferences.
- Early diagnosis of dementia affords an opportunity for helping PLWD to develop their individualized care plan based on their care preferences.
- Members of the health care team should instill hope and help empower the individual and their care-partner to thrive rather than simply survive.
- Encouraging cognitive rehabilitation and positive dementia care approaches, to enable independence, is key to functioning optimally and maintaining maximum independence.
- HIPAA requires that a provider obtain an individual's informed consent to disclose protected health information unless the individual is incapacitated.
- Care partners are valuable members of the health care team whose mental and physical health must be monitored and assessed over time.

Slide 7:

- In Module 2, we examined various criteria associated with a diagnosis of dementia, as well as the diagnostic criteria for specific types of dementias.
- In Module 4, we focus on practical considerations associated with providing a diagnosis of dementia—beginning with the benefits of providing a diagnosis of dementia during the early stages.

Slide 8:

- Early diagnosis affords an opportunity for early interventions and appropriate dementia care.
- PLWD want others to see and encourage their abilities, not focus on their inabilities.
- Persons living with dementia in the earlier stages can participate in the decision-making process regarding their own future medical treatments such end-of-life-related decisions.
- Early diagnosis enables PLWD and care partners to assemble a dementia interprofessional care team to facilitate stage-appropriate assessments of ability and use of positive approaches to meet and support ever-changing needs and abilities.
- Early diagnosis enables persons living with dementia and their care partners make continuous adjustments to their living environment to keep it functional and familiar.
- Available treatments can delay /slow progression of impairments and can reduce symptoms, behavioral problems, and functional declines in some persons.
- PLWD and care partners need ongoing instruction on what changes to expect and how to respond in a positive and supportive manner. See the listing of Resources, for instructional videos and written materials for care-partners and healthcare providers. Also see Module 8.
- PLWD and care partners must understand that medications delay decline but do not offer a cure.
- Behavioral problems are often responses triggered by the care-partner's actions or words, which were intended to be helpful but which may result in frustration and other emotions. See <https://daanow.org/resource-center/videos-and-films-about-dementia/>

Slide 10:

- An early diagnosis of dementia it is not always welcomed by PLWD or their care partners.
- A diagnosis of dementia can be highly stigmatizing, especially for some cultural groups and community members where there has been little to no instruction on understanding cause and effects of dementia and positive ways to help PLWD feel understood and welcome:
 - They may believe that dementia is contagious or associated with having defective genes.
 - They may perceive persons living with dementia as having a psychiatric illness.
- Family members may fear the impending financial obligations and caregiving burdens.
- The relief of having a diagnosis and being able to plan early for the future changes must be balanced against the fears, misperceptions, and realistic assessments of what the diagnosis means to the family structure. Be sensitive to these fears and offer hope, encouragement, resources, and referrals as appropriate and encourage wellbeing
- Family members may be negatively impacted because of the tremendous stigma associated with a dementia diagnosis in many diverse ethnic and cultural groups:
 - In the Chinese language the character used traditionally to depict dementia meant "crazy" (Guo, Levy, Hinton, Weitzman, & Levkoff, 2000)
 - In some Asian groups, dementia is thought to be due to the negative karma of one's ancestors; for other groups, evil spirits are thought to be in possession of the person (Hinton, Franz, Yeo, & Levkoff, 2005)
- In many others, early signs and symptoms do not signify dementia but are interpreted as "normal aging," and it is not until significant behavior problems appear (typically in the middle, not early, stages) that help is sought and a dementia diagnosis can be accepted.
- • There are links to resource materials with this module that are useful in helping family members understand the difference between what is normal aging and what is not.

Slide 11:

- An early diagnosis gives PLWD and care partners time to meet with specialists for financial planning, assigning power of attorney, and drawing up wills and living wills:
 - Many ethnic minority families do not create these documents until the disease has progressed to its end stages, making it less possible to respect the wishes of the PLWD since they can no longer participate in the discussion
 - When possible, providers should be cognizant of the cultural beliefs and values regarding such recommendations
 - As appropriate providers can make referrals to financial and legal specialists, who can prepare needed documents and assist with financial and legal issues at little to no cost.
- Early diagnosis allows PLWD to personally appoint a proxy decision-maker.
- Persons living with early-stage dementia have the time and ability to arrange and mobilize their financial resources and, if appropriate, apply for Medicare or Medicaid. They can also begin arranging their finances to address their anticipated long-term care needs.
- Other issues include driving privileges/cessation, obtaining other support services (such as in-home or institutionalized care), future treatment plans, and possible research participation.
- As appropriate, providers should refer PLWD and family members to local dementia care specialists and care coordinators, and Medicaid and Medicare eligibility workers.
- However, as with other major diseases, various factors prevent persons from receiving an early diagnosis. These include lack of access to affordable care, knowledge, denial, fear, and finances.

Slide 12:

- As is discussed in Modules 5 and 6, persons with early-stage dementia are still able to live independently. As dementia progresses into the middle-stage, the cognitive and functional impairments the brain changes caused by dementia become more apparent and the the cognitive and functional effects can no longer be denied or minimized. This may be the stage when PLWD and/or their care partners seek help from the medical profession.
- Middle-stage dementia is a more common time for minority groups to inquire about a possible diagnosis. They often wait until the behavioral responses are substantial; suggesting that something other than natural aging might be the underlying cause.
- No matter the stage at which an individual is diagnosed with dementia, it is important to provide the PLWD and their care-partners with hope, encouragement to stay engaged in meaningful life activities, appropriate resource materials and referrals, and regular follow-up.

Slide 13:

- There are many fears, misconceptions, and barriers to providing a person with a diagnosis of dementia—from both the provider and the person. In this next segment, we look at recommendations for providing a diagnosis.

Slide 14:

- Disclosing a diagnosis of dementia is a process that is best accomplished over the course of several visits.

- The diagnosis itself may evolve over time as the provider obtains necessary information from tests or other specialists.
- Timing of providing a diagnosis must balance many factors, including the needs and concerns of persons living with dementia and their family.
- Ideally, the diagnosis is provided by the primary care provider of the persons living with dementia, rather than the specialist. Also, other members of the team have valuable roles to play in assisting the primary care provider in delivering the news in a patient-centric manner (Min, Spear-Ellinwood, Berman, Nisson, & Rhodes, 2016).
- This module provides guidance on knowledge of resources and next steps needed by the primary care provider in order to best deliver this information.
- Even if additional testing had been involved in the diagnostic process, the care provider is most likely to have established a relationship with both the persons living with dementia and their family, and have gained insight into how to break the news.
- The provider should use an individualized, person-centered approach that is consistent with the expressed wishes of persons living with as well as the person's knowledge of dementia, personality characteristics, educational background, culture, and other pertinent circumstances.

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- A 2008 expert panel roundtable developed recommendations to help primary care providers talk about a dementia diagnosis with those affected. Disclosure is a process and not an event.
 - Encourage care partners to accompany PLWD to primary care visits. They can assist with communication and provide or substantiate information about the person's symptoms and history, and advocate for the PLWD's care preferences.
 - Ideally, the care partner will be involved in ongoing care partnering and decision making and can advocate for the wishes of the PLWD, take notes, and obtain any needed referrals for care; and update care plans and monitor/report ongoing changes.
 - If there is no identified care partner, suggest that a neighbor or friend accompany persons living with dementia to primary care visits.
 - If PLWD already have moderate memory impairment, have the care partner take notes
 - If a social worker or other professional is involved in the care, they should attend primary care visits in person or via telecommunications.
 - Be sure to comply with HIPAA regulations when disclosing information.

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- Use a private, comfortable location, schedule ample time for the visit, and minimize distractions
- Provide care that is culturally sensitive and linguistically appropriate. Use easy-to-understand words and avoid medical jargon (See Module 3 for additional guidance)
- Use the proper name of the diagnosis--"Alzheimer's disease," Lewy body dementia, or Parkinson's disease dementia, when providing the diagnosis (unless persons living with dementia specifically indicate otherwise).
- Emphasize the current capabilities of the person and note that these can likely be preserved for a reasonable amount of time, especially if the persons living with dementia are in an early stage.
- Emphasize the benefits of staying physically active, eating heart healthy foods, drinking fluids, being socially engaged, and participating in meaningful daily activities.

- Emphasize the benefits of medications, lifestyle changes such as exercising and remaining socially active, and planning ahead.
- Discuss the benefits of non-pharmacological everyday activities and approaches to enhance wellbeing. This may include doing household chores, story telling, reminiscence, touch, nature walks, and other meaningful activities based on the individual's abilities and preferences.
- Primary care providers can establish themselves as a member of the interprofessional team and advocate for both persons living with dementia and their care partner(s). The provider can be instrumental in providing information, educational resources, and referrals.
 - The provider should promote the benefits of socializing (such as adult day care programs and support groups).
 - The provider can also discuss opportunities to be a part of clinical trials.
- At a minimum, PLwD and care partners need information about what to expect over the next six months. See Resource Section for booklets, pamphlets, websites, and other resources.
- Document specific issues addressed and those needing to be discussed.
- Follow-up appointments should be scheduled every three-to-six months.

Slide 18:

- Although there are updated diagnostic criteria, the guidelines for sharing a diagnosis of dementia or Alzheimer's disease are outdated.
- As with many life-changing diagnoses, reactions to and readiness for a diagnosis may vary among persons living with dementia and their family members and care partner(s).
- Providers need to consider whether the PLwD want to receive a diagnosis.
 - Within HIPAA regulations, reach out to spouses or care partners to determine whether they think that the persons living with dementia are ready to receive a diagnosis
 - Consider the capacity of PLwD, and whether they are ready/able to understand the diagnosis. Capacity is a functional assessment/clinical determination, not a legal one.
- If PLwD are unwilling to receive the diagnosis, the primary care provider must still explain that a neurological problem exists which over time will affect their abilities and for which there is medical treatment, but not a cure, and that they are likely to require additional assistance and care in the future. They should state that the course of dementia varies by individual and is affected by many factors. Many people diagnosed with dementia have years of productive and enjoyable life ahead.

Slide 19:

- Competency is a legal determination made by a judge in court.
- As will be discussed in detail in Module 11, primary care professionals can make clinical determinations of capacity. Capacity is a functional assessment that includes four standard decision-making abilities:
 - Understanding
 - Appreciation
 - Expressing a choice
 - Rationalization or reasoning

Slide 20:

- As dementia progresses, the brain changes affect memory, comprehension, judgment, problem solving, and communication abilities, which may influence a person's capacity to provide informed consent for specific treatments and care partnering plans.
- Persons living with dementia who are unaware of their memory impairments may have diminished decision-making capacity compared with those who are aware of their impairments:
 - Providers can use a directed clinical interview along with other formal capacity assessment tools, thus integrating a cognitive and physical assessment along with ancillary tests and information
 - However, this approach may be particularly challenging when working with PLwD from ethnic and racial minority populations, as there may not be specific tests available to meet their specific language needs. In addition to language barriers, they may also have education levels and comprehension aptitudes. These issues are addressed in Module 3.
- The most commonly used clinical tools for assessing medical decision-making capacity include:
 - The MacArthur Competence Assessment Tools for Treatment (or MacCAT-T)
 - The Capacity to Consent to Treatment Instrument (or CCTI)
 - The Hopemont Capacity Assessment Interview (or HCAI)
- When the capacity of PLwD is not clear, situations may call for formal assessment, including:
 - When judicial involvement is anticipated
 - When family members and other decision-makers disagree on treatment or care planning
 - When a decision about undertaking a risky treatment is needed
 - When a person's participation in clinical trials is contemplated

Slide 21:

- Primary care providers are reluctant to make a clinical diagnosis of Alzheimer's disease.
 - There may be uncertainty about the need and the utility of a diagnosis (Dubois et al., 2015; Grossberg, Christensen, Griffith, Kerwin, Hunt, & Hall, 2010)
 - Providers can perform appropriate tests to rule out possible reversible causes of the symptoms if there are questions about the diagnosis (Grossberg et al., 2010)
 - Providers unsure about what PLwD's best interest is (Dubois et al., 2015)
- Primary care providers may fear the potential harm of a dementia disclosure (such as suicide, concerns about negative attitudes towards persons living with dementia and their care partners, and recognition that a diagnosis of dementia is life changing). Primary care providers must be watchful for potential harm when disclosing other life-changing diagnosis.
 - If adverse reactions occur, providers should make a referral to an appropriate mental health professional
- To overcome these barriers, primary care providers need to recognize the benefits of early diagnosis both on the disease course as well as the quality of life of PLwD and their care partners. Primary care providers also need to recognize the reluctance of some PLwD and family members to receive information related to a diagnosis of dementia. Benefits to the PLwD and care partner(s) are not always obvious and may require a period of adaptation/adjustment until more information is desired and/or sought.

- It's important to consider and discuss issues of access to affordable and appropriate care, which can become a barrier to providing a diagnosis of dementia and appropriate ongoing care and resources.
- Reluctance on the part of the healthcare provider may also be the result of inadequate knowledge of the different types of dementia and the individual changes in needs and abilities associated with each.

Slide 22:

- This final segment covers how to discuss a diagnosis of dementia with persons living with dementia and their care partner(s). Providing a diagnosis of dementia may be challenging to all involved, including providers. We will look at how to address persons living with dementia who are in denial; address capacity issues; and discuss HIPAA regulations.

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- Like many other diagnoses, there are far-reaching consequences associated with a diagnosis of ADRD. The provider must be aware of and sensitive to these consequences and should
- Address persons living with dementia directly and maintain eye contact, if culturally appropriate.
 - In many non-European cultural groups, eye contact is disrespectful. Providers need to be sensitive to this issue and not assume that direct communication is the optimal approach. For example, in many Asian cultures, indirect communication is preferred and eye contact is avoided. This is also true of many Middle Eastern cultures.
 - Providers might want to receive training in cultural competence or cultural humility
- Assess the current abilities and strengths of the persons living with dementia and emphasize their abilities and ways to help maintain their abilities while sharing the diagnosis.
 - The provider should also assess persons living with dementia for depression and refer them to pharmacotherapy or psychotherapy if needed and appropriate. See modules 6 and 8 for additional information.
- Assess persons living with dementia for risk of suicide.
- Gauge the educational levels of persons living with dementia and their care partners present information accordingly.
- Be aware of, and sensitive to, the type of explanation preferred: cautious and reserved vs. objective and precise language.
- Be aware of any sensory changes such as hearing or vision problems and changes in communication that may interfere with the dialogue.

Slide 24:

- If the persons living with dementia are capable and willing, obtain their consent to inform family members or other care partners about the diagnosis in a family conference or group meeting. We will discuss 'capacity to provide consent' in greater detail in Module 11
- If not, document in the record if they indicate that they do not want to inform family members or if they do not have capacity to decide and why it is in the best interest of their wellbeing, safety, medical care, and so forth to disclose the diagnosis to family and care partners.

- Ask the persons living with dementia and their care partner(s) if they have questions.
- If possible, provide materials for the persons living with dementia to take home. These materials can be written or found on Web sites.
- Schedule follow-up appointments to discuss what to expect as a result of the diagnosis, and for follow-up treatment.

Slide 27:

- Most surveys find that the majority of unaffected older persons, as well as persons living with memory complaints, would want to know their diagnosis if they or a spouse had a diagnosis of dementia.
 - Many of these studies were conducted with English-speaking persons who possessed adequate health literacy.
 - It is important to note that similar surveys have not been conducted with racial, ethnic, and culturally under-represented groups in the United States.
- A recent study suggests that people are less willing to have a diagnostic assessment or screening after being informed of the potential benefits and risks of a diagnosis of dementia (Robinson et al., 2014).
- For example, in community samples, the majority of persons without cognitive impairment (91 percent) are in favor of disclosure of a diagnosis. However, studies of persons already diagnosed with dementia or in a memory clinic find that 85 percent were in favor of disclosure (Van den Dungen, van Kuijk, van Marwijk, van der Wouden, van Charante,...& van Hout, 2014). Persons agreeing with disclosure focused on issues of autonomy and the possibility of planning one's future; arguments against disclosure focused on the fear of getting upset and the perception that knowing the diagnosis has no value.
 - Another study surveyed persons ages 65 and older who did not have a diagnosis of dementia and were attending primary care practices. A total of 545 persons completed the Perceptions Regarding Investigational Screening for Memory in Primary Care (or PRISM-PC) questionnaire. The results showed that: 63 persons screened positive
 - Of those, only 21 (33 percent) accepted and 42 (67 percent) refused diagnostic assessment
 - Refusing diagnostic assessment was associated with the perceived negative attitudes of dementia and living alone.
 - Persons reluctant to undergo screening perceived minimal benefits of screening, and were also less likely to undergo screening for other conditions.

Slide 28:

- Fear of progressive memory impairment and other behavioral or psychiatric symptoms can cause persons living with dementia to experience denial.
 - However, not all memory impairment is attributable to Alzheimer's disease or other dementias; it can be due to a vitamin deficiency, infection, or unrecognized/untreated depression or delirium.
 - Evaluation of memory impairment includes consideration of possible treatable causes.

- Providers should be aware that PLWD may be suffering from anosognosia—or a lack of awareness of his/her cognitive impairment. The person may react with anger if confronted about having cognitive or memory impairment issues.
- However, it is important to realize that lack of insight is not the same as denial.
- The provider should deliver a dementia diagnosis in a thoughtful, sensitive and truthful manner, but it is not the provider's job to convince someone they have dementia. In other words, providers don't want to argue about this. If, once the diagnosis has been delivered, persons living with dementia continue to reject the diagnosis; the provider may need to work with the care partner(s) more directly (within HIPAA parameters).
- The provider must present information explaining the diagnosis. If the person refuses to believe the information, the provider must make sure the care partner has the information, even if the person does not want to share it.
- As appropriate, make referrals to local support groups through the Alzheimer's Association or other groups to help maintain the wellbeing of the PLWD and their care partners.

Slide 29:

- PLWD (and other life changing diseases) suffer from the symptoms of their disease—and the reactions of others. They may also hold various misperceptions and fears regarding dementia.
- These fears can prevent people from seeking a diagnosis.
- Cultural beliefs or misperceptions can lead to an unwillingness to receive a diagnosis.
- Dementia has a considerable impact on a person's identity. Persons diagnosed with dementia and their care partner(s) often report feelings of loss, anger, uncertainty, fear, and frustration. As we discussed in Module 3, there are some differences in how different ethnicities perceive these negative attitudes.
- For persons who were aware of their progressive impairments, receiving a diagnosis may be a relief—an explanation of why they were changing.
- For all persons living with dementia and their care partner(s), getting a diagnosis of dementia requires considerable adjustment.
- They also require instruction about their changing needs and abilities and ways to support and maintain their independence and overall health and wellbeing.

Slide 30:

- Sharing a person's diagnosis of dementia with family members, other relatives, or potential care partners must follow HIPAA privacy protections (CDC, 2003).
- HIPAA's provision allows a provider to obtain an individual's informed consent to disclose protected health information related to involvement in care or payment of care to specific family members, relatives, friends, or anyone else that an individual has deemed to be appropriate.
- If persons living with dementia refuse to allow the provider to share relevant information with family or care partners, the provider's job is not done. The decision should be addressed at each visit.
- HIPAA's provision allows a provider to disclose protected health information in cases where an individual is incapacitated if, in the provider's professional judgment, the disclosure is in the best interests of the individual.

- If the person is not incapacitated, his/her wishes need to be respected. Providers must provide the best care possible and respect the care preference and boundaries of PLWD.
- Providers should document the rationale for their decisions in the records of persons living with dementia. That information should include what, if any, elements of the person's decision-making capacity are impaired; with whom, if anyone, the information is to be shared; and why or why not it is to be shared.

Slide 31:

- A diagnosis of dementia affects more than the PLWD; it can cause significant changes and distress for the spouse and other family members.
- Within HIPAA policies, include spouse or care partners in all of the visits and decision-making.
- Providers can use the best practices of disclosing a dementia diagnosis discussed earlier:
 - Use a private, comfortable location; schedule ample time for the visit; and minimize distractions, such as phone calls and pagers
 - Use the proper name of the diagnosis -- "Alzheimer's disease", Lewy body dementia, or Parkinson's disease dementia, when providing the diagnosis
 - Provide care that is culturally sensitive and linguistically appropriate. Use easy-to-understand words and avoid medical jargon (See Module 3 for additional guidance)
 - Emphasize the current capabilities of persons living with dementia and note that these can likely be preserved for a reasonable amount of time, especially if the person is in an early stage of dementia
 - Emphasize the benefits of lifestyle changes such as regular physical exercise, eating a heart-healthy diet and remaining socially active; and planning ahead
 - Emphasize the benefits of medications as appropriate, and monitoring and maintaining healthy blood sugar and blood pressure levels
- It is important that the interprofessional health care team check in with care partners to make sure that they are taking adequate care of themselves. Care partners need to maintain a healthy lifestyle, including a healthful diet, regular exercise, and adequate sleep to continue caring for persons living with dementia.
- Providers should try to speak with care partners separately to obtain information about the persons living with dementia and to discuss what the diagnosis means for them.
- Both the persons living with dementia and his or her family and care partner(s) need time to adapt to the diagnosis and to assimilate it into their new identity.
- As we discussed in detail in Module 3, the health care team should be cognizant of and sensitive to issues of ethnic, cultural, and racial diversity when discussing the diagnosis.
- Care partner concerns include the following:
 - Do we socialize? If so, how?
 - How do we protect our loved one yet give him/her independence?
 - How do we deal with our anxiety about the future?
 - How do we establish our new norms?
- Providers can help the care partner(s) navigate the health care visits and can provide consumer resources and support services.
- Providers should consider the use of telemedicine options for follow up with individuals who do not have ready access to healthcare professionals

- Providers should emphasize that there is time to adapt and that the progressive decline is rarely rapid. PLwD may retain their identity, personality, and certain cognitive and functional capabilities for some time. However, it is important to provide objective information about what the care partner(s) should expect in the near future—say, the next six months.
- Providers should explain how to control symptoms and improve the quality of life for PLwD.
- The care partner(s) need to plan for the possibility that they may eventually need to arrange for more help at home or for residential care for the persons living with dementia.

Slide 32:

- Care partners frequently suffer from depression or other stress-related disorders and report a significantly reduced quality of life.
- There is a need to provide positive instruction to care partners on communication strategies and care approaches to help maintain the independence and wellbeing of the PLwD.
- Providers need to routinely assess care partners for changes in sleep habits, appetite, and stress and make referrals to behavioral health and wellness providers in the community.
- The care partners may be unaware of, uncomfortable with, or afraid to ask for help with day-to-day caring activities, needing financial and emotional support, and needing personal time away.
- Providers should provide guidance for finding resources such as local support organizations, which offer dementia care instruction and care coordination, creating meaningful moments for the PLwD, affordable home care and respite care, local spiritual and religious services, and other support services to enhance the wellbeing and satisfaction of the PLwD and care partners.
- It is important to help the care partners understand the brain changes caused by dementia and the effects of those changes on senses, emotions, communication and understanding, and functional independence. Providers can help care partners recognize and support the PLwD's changing needs and abilities and prepare for future changes regarding behavioral responses to success, fear and frustration, as well as safety concerns, driving cessation, financial and legal considerations, and ultimately a range of end-of- life decisions.

Slide 33:

- The care partner(s)' health and quality of life influences the health and quality of life of persons living with dementia.
- Generally, as the disease process continues, there is a need for more care partners to share in the care partnering and support of the PLwD and the spouse of other family care partner.
- Research has indicated that increased caregiving burdens on the care partner(s) are detrimental to the quality of life of persons living with dementia.
 - However, there are many evidence-based programs that are designed to help lower stress in care partners. And, studies have shown that lower levels of stress in the care partner are associated with better quality of life for persons living with dementia.
 - Findings from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project demonstrate the effectiveness of tailored multi-component interventions in reducing caregiving burden and depressive symptoms in care partners of persons living with dementia.

Slide 34:

- There are circumstances that warrant a referral to a specialist, memory clinic, or other specialty center for additional evaluation:
- Neurologist: If persons living with dementia are younger than age 65, have prominent mood or psychiatric symptoms, have a rapid progression of symptoms, or present with other neurologic findings not usually seen with Alzheimer's disease, they should be referred to a neurologist.
 - For example, a recent study found that diagnosing a non-Alzheimer's dementia, specifically a behavioral variant frontotemporal disorder (or bvFTD), was particularly difficult for primary care practitioners and non-specialists (Shinagawa, Catindig, Block, Miller, & Rankin, 2016). In fact, 60 percent of persons given a diagnosis of bvFTD by a community provider did not have the disorder according to specialists.
- Psychiatrist or geriatric psychiatrist: When further assessment is needed to determine whether depression or another mental health condition is causing or contributing to the persons living with dementia's symptoms, they should be referred to an appropriate psychiatrist.
- A neuropsychologist can provide a detailed assessment of mental functioning or status. A Neuropsychological assessment is helpful for highly educated and highly functional persons living with dementia or those in early-stage disease, particularly when traditional tests are not sensitive enough to indicate the presence of any problems.
- Other mental health providers such as psychotherapists, mental health counselors, licensed clinical social workers (LCSW), and psychologists (among others) can provide effective, evidence-based nonpharmacological treatment to PLwD, family members, and care partners.
- Alzheimer's disease center or tertiary care center's memory clinic: When persons living with dementia are interested in participating in clinical trials or need guidance for complications, a referral to an Alzheimer's disease center or tertiary care center's memory clinic may be appropriate.
- Other community resources— The Alzheimer's Association, National Stroke Association, National Parkinson Foundation, Association for Frontotemporal Degeneration, and Lewy Body Dementia Association may all be appropriate resources for persons living with dementia.
- Ideally, it is best for a primary care provider to develop a network of specialists for referrals. It is important to consider and include telemedicine and telehealth options to fill in gaps within the specialist provider and community network.
- Once a diagnosis of dementia has been made, the needs of both persons living with dementia and their care partner(s) will continue until death. Support services are available in many communities to assist on this journey. Persons living with dementia and their family members or care partners are not alone. There are services and resources that can help them at all stages of the disease. Module 9 specifically addresses all of the potential members of the interprofessional team, and Module 12 addresses the continuum of care.

Slide 35:

- These items are provided to allow faculty to evaluate what students have learned. The items can be used in several ways including given at the end of the lecture to assess knowledge or as a pre-post test to assess knowledge gain. These items have face validity. Psychometric testing was not conducted on these items.

Answer:

1. d. Avoid medical jargon

Slide 36:

Answer:

2. b. Provide realistic expectations of disease progression over the next 3 to 6 months

Slide 37:

Answer:

3. a. A provider must obtain the individual's informed consent before disclosing any information unless the individual is incapacitated.

Slide38:

Answer:

4. b. The person with likely dementia is younger than age 65