

**FACULTY GUIDE**

**Supplemental Module 1**

**Providers and Caregivers as Allies**

**May 2017**

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**Slide 1:**

- Providers and Caregivers as Allies: This module is intended to give health care providers ideas about how they can better support caregivers who are caring for persons living with dementia. It is part of a module series that was developed under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. This work was funded by the U.S. Department of Health and Human Services, Office of Women's Health.

**Slide 2:**

- By the end of this module health care providers will be able to describe ways to support caregivers and protect their health, and how to recognize and address caregiver stress.

**Slide 3:**

- Informal, or unpaid, caregivers supply approximately 85% of all the care given to older adults. By one estimate, in 2014, caregivers provided an estimated 18.1 billion hours of unpaid assistance, valued at about \$221 billion dollars. Persons living with dementia who have caregivers have lower Medicare costs than those who do not. At the same time, caregiving comes at a cost. Caregivers of persons living with dementia often face great emotional, social, physical, and financial costs. As health care providers you must be aware of those costs and how to help caregivers address them.

**Slide 4:**

- Caregiving is a task performed primarily by women. About two-thirds of those caring for people living with dementia are women, of which about one third are daughters. More than twice as many female caregivers as male caregivers report spending 21 to 60 hours a week providing care. About two and a half times as many women as men report living full time with the person living with dementia.

**Slide 5:**

- Caregivers are important allies for health care professionals. They are the ones who are closest to the person receiving care and are in a position to make useful observations and make certain medical instructions are carried out as intended. According to the Dementia Measures Workgroup, an interdisciplinary group of experts, family caregivers' knowledge, well-being and sustained engagement with healthcare providers are all critical to the success of both medical and psychosocial components of caring for persons living with dementia.

**Slide 6:**

- When working with most caregivers and persons living with dementia, the principles of person-centered care should apply as much as with any other care relationship. In the context of person-centered care, individual values and preferences are elicited from the persons living with dementia and, once expressed, guide all aspects of their care, supporting their realistic health and life goals. When persons living with dementia are unable to express these values and

preferences, then the caregivers, partners, and family members should be asked to provide that guidance. You should always keep in mind that person-centered care differs across cultures. If you are not familiar with a particular culture you should seek the guidance of someone who is familiar with it in order to ensure that you are respecting cultural expectations when providing dementia care.

**Slide 7:**

- The essential elements of person-centered care include an individualized, goal-oriented care plan based on preferences expressed by the person living with dementia and the caregiver. There has to be ongoing review of the goals and care plan as the dementia journey unfolds. The care should be supported by an interprofessional team that includes the person living with dementia and the caregiver as essential members. One primary or lead point of contact on the health care delivery team is necessary to ensure that there is active coordination among all health care and supportive services providers that involve the documented conversations that are face-to-face or by phone.

**Slide 8:**

- In order to implement and improve person-centered care, there must be active coordination and information sharing among all health care and supportive services providers that involve documented conversations that are face-to-face or by phone. To accomplish this, all members of the health care team may need to be trained in effective communication. Feedback from persons living with dementia and their caregivers will help you determine when you are providing quality of care and meeting their expectations.

**Slide 9:**

- Caregivers play a number of roles over the course of giving care and in their interactions with health care providers. They provide day-to-day care and are care coordinators. Caregivers may be the clearinghouse for information about medical conditions and other kinds of information such as financial issues. They serve as advocates. They recognize and validate feelings experienced by the person living with dementia and help these older adults deal with those emotions and feel supported. They serve as sentinels to assure that quality of care is maintained.

**Slide 10:**

- Each year caregivers provide approximately 18.1 billion hours of assistance. This assistance may include activities of daily living (such as bathing, transferring, dressing, eating, personal hygiene, and toileting) and instrumental activities of daily living (which include housework, preparing meals, managing finances, shopping, communicating by phone or other means, and managing transportation). It may also include reminders and cuing in everyday tasks for persons living with dementia. Caregivers also ensure that persons living with dementia do not come to harm through actions like wandering, accidentally setting fires, and ingesting inedible food.

**Slide 11:**

- Caregivers frequently serve as care coordinators. Because persons living with dementia are often cared for by many different health care and service providers, the caregiver may, in essence, become the information clearinghouse. While the primary care clinician has a major role in coordinating care across multiple health care providers, it is the caregiver who meets with all providers. As a result, caregivers are often the most knowledgeable about the treatments that are prescribed and can effectively coordinate care, making sure that treatment plans are implemented.

**Slide 12:**

- As information resources, caregivers are a primary source of information about medical diagnoses, medications, and medical equipment that health providers prescribe for persons living with dementia. You can ask caregivers whether other health care providers are also treating the persons living with dementia and if caregivers have any concerns about interactions between medications or other conflicts. Caregivers can remind all health care providers of the goals and preferences of persons living with dementia, especially as the dementia progresses and the patients are no longer able to speak for themselves.

**Slide 13:**

- In the role of advocate, caregivers may request additional care or resources for the person living with dementia. Despite the pressures on the time of health care providers, it is important to ensure that these requests receive the attention they deserve. Caregivers often have useful insights. Whenever possible, providers should seek to create a collaborative relationship with caregivers. They should acknowledge the legitimacy of the caregiver's perspective and emphasize the need for joint planning, goal setting and decision-making (which should also involve the person living with dementia). These discussions should emphasize clear, realistic goals. For example, health care providers will need to establish how to communicate with the caregivers, taking into consideration available resources, such as e-mail. Risk tolerance is another important issue to cover. Health care providers should discuss how much autonomy caregivers and family members are willing to accept for the person living with dementia and how much risk to tolerate.

**Slide 14:**

- An important caregiver role is providing emotional support. Caregivers who display kindness and use positive strategies help persons living with dementia cope with their changing abilities. Caregivers should be encouraged to comfort persons living with dementia when they are upset – holding their hands, giving a gentle hug, or talking calmly to reduce agitation. These forms of non-verbal communication become especially crucial in the later stages of dementia. Encourage caregivers to reinforce positive feelings and behaviors when they occur – this makes it more likely that these behaviors repeat. However knowing how to provide emotional support takes practice and help. You can also recommend that caregivers improve their caregiving skills by taking a communications course at a local college or chapter of the Alzheimer's Association. You

may recommend that the caregiver read *The 36-Hour Day* by Mace and Rabins to better understand how they can become stronger emotional supporters.

**Slide 15:**

- Not only do caregivers play an important role in making certain persons living with dementia receive high-quality care, they also play an important role in quality improvement. Caregivers are often the first to detect and report problems in care. These early warnings can benefit everyone. They should be taken seriously. However, false alarms can occur. Some caregivers may be overenthusiastic in reporting problems, and when this occurs health care providers, in collaboration with the caregiver, should identify the best modes of communication.

**Slide 16:**

- Caregivers are your allies, and it is important to help them take care of themselves. Remind caregivers to pace themselves and seek respite as needed. There are multiple types of respite you can recommend, including at-home assistance such as Meals-on-Wheels, chore services, and help from other family members. You can also recommend out-of-the home services such as adult day services and encourage them to take classes in caregiving from the local Alzheimer's Association chapter, Area Agency on Aging or local community college. One amusing book called *The Selfish Pig Guide to Caring* by Hugh Marriott may be helpful in providing perspective on the guilt caregivers often feel about accepting respite. It is important to assess and treat depression or anxiety in caregivers. If you are not the primary care provider for a given caregiver, you should encourage that person to seek care from the provider who is. You should also be alert for any tension within the family that could negatively affect the primary caregiver and then work with the caregiver to acknowledge and address that conflict.

**Slide 17:**

- Families are always in the background and can play an important role in the lives of caregivers. Some families are close knit, others are not. In families with long histories of conflict, disagreements may add to the stress of caregiving and decision-making. Ideally, other family members can support the caregiver by assuming a part of the workload. When decisions are made, it's important to arrive at consensus, but getting there can be hard work or not possible. When working with families, health care providers may want to advise them to hire a case manager to facilitate the decision-making process, or encourage them to seek guidance from an Area Agency on Aging. Good dementia care results when the health care team makes recommendations that help support both the caregiver and the care recipient.

**Slide 18:**

- On this slide you can find several resources to share with caregivers to help them better understand the value of counseling and support groups.

**Slide 19:**

- Let us now see how well you can address learning objective #1: Describe ways to support the caregiver.

- An 83-year-old woman was found wandering around her neighborhood. She was brought to the Emergency Department and ultimately diagnosed as having moderate dementia. Her daughter is working full-time but feels a need to stop working to take care of her mother. What can you do for this caregiving daughter? Check your answers against the suggestions found in the next slide.

**Slide 20:**

- There are several items you should discuss with the daughter. First, determine what kind of caregiver support is available. Can the daughter provide care full-time or share caregiving with paid help or day care services? Are there family members who can share the caregiving load? Next, talk with the daughter about barriers that may impact her caregiving. Does she have competing responsibilities and does she **want** to be a full-time caregiver? It may be reasonable to suggest a family meeting to discuss possible options for home assistance from other family members. Remind her also to consider changes that she may need to make if full-time home care does not work. As the daughter takes on the caregiving role, she will be subject to new stress and should be made aware of caregiver stress. Encourage her to talk about her concerns with you as needed and monitor her for stress every time she visits your office.

**Slide 21:**

- Many caregivers have multiple other responsibilities, as parents, spouses, and workers, that compete with their caregiving. It is important to appreciate the caregivers additional work load and stress that may result from these multiple pressures. Because caregivers may be reluctant to admit to pressures, health care professionals need to be proactive in looking for signs of caregiver stress. Clinicians may want to consider administering a formal stress assessment. The URLs shown on this slide offer a series of tools that can be used to assess stress. Health care professionals can use the Caregiver Well-Being Scale to help caregivers access their caregiving and improve the activities they are not performing well in by making adjustments or getting additional help. The internet links on this slide were last accessed on June 15, 2017.

**Slide 22:**

- There are a few basic principles of assessing caregivers. The assessment should include the needs and preferences of both the person living with dementia and the caregiver. They should be periodically updated to reflect changes in either the caregiver or the care recipient. They should identify both strengths and problems in caregiving delivery. And they should reflect the culturally competent practices appropriate to the caregiver/care recipient dyad. It is also important to encourage caregivers to set aside time to assess themselves regularly as a basis for more effective self-management of their problems. Without self-awareness it is difficult to effect change.

**Slide 23:**

- You can help caregivers in many ways. You can offer to refer them to try stress reduction through a mindfulness based stress reduction program. You can also advise them to join a local dementia support group or self-help program. Encourage them to make their health a priority by suggesting appropriate exercises and nutrition, keeping in mind caregivers' needs,

preferences, and priorities. Be alert for depression. Simple tools like the Patient Health Questionnaire (PHQ-9) discussed in another module in this series can help identify potential depression. You should refer such caregivers to a mental health provider and/or community resources for support and assistance.

**Slide 24:**

- Let us now see how well you can address learning objective #2: Describe ways to protect the caregiver's health.
- A 55-year-old female caregiver with a history of diabetes and hypertension comes into the office and has a complaint of feeling fatigued.
- What are you going to ask this caregiver? Check your answers against the suggestions found in the next slide.

**Slide 25:**

- A report of fatigue should trigger a discussion on sleep patterns to determine if there is anything that is disrupting normal sleep or if the fatigue may be related to health problems. This caregiver should be asked if she is having trouble keeping her diabetes under control. Is she eating regularly and getting at least some exercise? Is she checking her blood pressure regularly and is it under control? It is important to discuss caregiving stress and acknowledge that it places a burden on the caregiver. Caregivers should be reminded of the importance of caring for their own health. If needed, screen for depression and refer her to counseling, if it is indicated.

**Slide 26:**

- A number of other referral options are available to help caregivers manage stress. There are educational and skill building programs in most communities. Caregivers need to learn how to manage problem behaviors in persons living with dementia. They should also learn stress reduction skills to improve their ability to cope, reduce negative thinking patterns, and plan for the future, from a care perspective and financially. People who need more help should be referred for individual or family counseling or therapy. Some may find speaking with a clergy member to be useful.

**Slide 27:**

- Let us now see how well you can address learning objective #3: Describe how to address caregiver stress in the following scenario.
- A 58-year-old female caregiver describes problems dealing with her mother who has advanced dementia. What can you recommend for this caregiver? Check your answers against the suggestions found in the next slide.

**Slide 28:**

- Ask the caregiver to talk about the specific problems she is experiencing and help her find pragmatic solutions. To help her begin, ask why she is feeling stressed by the caregiving. Once you identify the problems, discuss possible options on how to share the workload with family or through paid help. You may suggest respite options and, if you sense resistance, remind her that

burn out will prevent her from providing good care. Depending upon the amount of stress, it may be reasonable to suggest a trial use of adult day care or to consider institutional care. Be sure to ask the caregiver about her own health, paying particular attention to any specific co-morbid conditions that may impact her ability to provide the level of care she wants. You can also perform a formal stress assessment to demonstrate the true level of her stress. Depending upon the problem identified, a referral to a local class on managing difficult behaviors or stress may be indicated.

**Slide 29:**

- Persons living with dementia and their caregivers come from an array of cultures. Their heritage and language preferences can affect their help-seeking behaviors and access to care. More is known about African Americans, Hispanics and Chinese Americans than about groups like the lesbian, gay, bisexual, transgender (LGBT) community, American Indians, and Native Hawaiian populations. The creation of a health message that recognizes and reinforces a group's cultural values, beliefs, and behaviors to provide context and meaning about a given health issue requires substantial insight into a culture. If you feel unprepared to culturally tailor your dementia care to make it suitable for people from another culture, find someone from that culture to help you communicate better.

**Slide 30:**

- In summary, caregivers are very valuable allies of health care providers in caring for persons living with dementia. They should be actively involved in care discussions that take place to ensure that the needs and preferences of the person living with dementia are acknowledged and addressed. Support them in performing their roles and responsibilities with referrals to home and community-based services, assessments of caregiver stress and burden, and suggestions about possible classes in skill development. Help them protect their personal physical and mental health. Healthcare professionals should be proactive in looking for signs of stress and depression in caregivers and make sure that affected individuals are referred for treatment.

**Slide 31:**

- This and the next two slides contain the full references of material mentioned in the module. The internet link on this slide was last accessed on June 15, 2017.

**Slide 32:**

- The internet link on this slide was last accessed on June 15, 2017.

**Slide 34:**

- The URL link on this page takes the user to a series of videoconferences on dementia that were supported by grant number UB4HP19205 at the University of Nevada between 2010 and 2015 from the Health Resources and Services Administration (HRSA), an operating division of the U.S. Department of Health and Human Services (DHHS). Videoconferences on the topics discussed in this module include "Care Training on Dementia," "Alzheimer's Disease and Memory Loss,"

“Healthy Brain/Healthy Body,” “Healthy Self-Care,” “Stress Management for Caregivers of Older Adults,” and “Coping with Changes Of Alzheimer’s Disease and Mental Health Disorders.”

The internet link on this slide was last accessed on June 15, 2017. The other links are to resources for caregivers that are on the Alzheimer’s Association website.