FACULTY GUIDE

Supplemental Module 3
How Clinicians Can Interact Effectively with Caregivers

May 2017

Slide 1:

- How Clinicians Can Interact Effectively with Caregivers: This module is intended to make clinicians aware of issues around interacting productively with caregivers of persons living with dementia.

Slide 2:

- At the conclusion of this module, providers on the health care team should better understand the importance of forming positive partnerships with caregivers who provide care to persons living with dementia. They should also know how to establish and maintain these partnerships. In addition, they should be able to discuss their responsibilities as a member of the provider/caregiver dyad.

Slide 3:

- In today's health care environment, patient-centered care is a basic competency. The world of chronic disease care requires active involvement of health care providers with persons living with dementia and by extension, their caregivers. Caregiving has to be a partnership between the caregivers and the providers involved. There are pressures in the health care environment to produce more quality and satisfaction while reducing cost. These pressures provide a strong argument for working more effectively with caregivers. Caregivers can help primary care providers and the other members of their health care teams by supplying additional information and by supporting care plans.

Slide 4:

- It is important to make caregivers an integral part of the care team and respect their input. Not all communication needs to be in person and various communication modalities, such as the telephone and e-mail, can be used effectively. In care management, the shared goal of providers and caregivers is to detect and treat problems early to prevent small problems from escalating into larger issues. Ideally, care should be based on timely notification of unexpected changes in condition, such as a fall, being confused, or the appearance of a rash.

Slide 5:

- Ideally, the health care team includes providers, the person living with dementia, their partners and family members, and the caregivers. Such a team provides reciprocal benefits and responsibilities. The caregivers oversee the regimen at home. In doing so they are able to quickly report changes in status. Providers explain the risks and benefits of treatment options. Providers and caregivers work jointly on decision-making, actively involving the person living with dementia whenever possible. When providers respond quickly to queries from caregivers they enable caregivers to be more effective partners.

Slide 6:

- The health care provider's view of the provider/caregiver interaction is often quite different from that of the caregiver. Providers often believe that they provide far more information than caregivers report has been given to them. The use of jargon and technical terms contribute to this mismatch. Studies suggest that caregivers report less depression when a provider emphasizes the importance of the caregiving role and listens to the caregiver's needs and concerns. The next several slides provide additional information on ways to improve communication.

Slide 7:

- There are a number of basic components to effective interactions with caregivers in addition to teaming, which was just discussed. They include improving communication through listening, responding, respecting, informing, and teaching. The final component is evolving, which addresses the team response when changes occur in the health and well-being of the person living with dementia. Each of these components will be discussed in this module.

Slide 8:

- The value of listening cannot be overestimated. The first principle of effective communication is that all parties need to feel acknowledged. Because the provider/caregiver dyad is often an unequal partnership, caregivers may feel ignored. If they do not think you listen or value their input, they may withdraw. Techniques for active listening are taught in many training programs but are hard to implement. At a minimum, you should find some time, even briefly, to actively listen to the caregiver's concerns and respond thoughtfully to their questions.

Slide 9:

- The best way to show you are listening to caregivers is by responding to their questions. Sometimes it is helpful to repeat the question or to paraphrase it. You can pose the question again to better understand it or its implications. The nature of the response depends on the content of the question. It is important to distinguish information from opinion and advice. Some queries involve caregivers reporting changes in the health status of the person living with dementia. They should be treated as legitimate observations worth exploring and discussing.

Slide 10:

- Caregivers need to know the rest of the health team values their opinions and observations. Their input should not be dismissed with only a quick reassurance. Caregivers' advice should be sought when appropriate. Whenever possible, they should be involved in decision-making, along with the person living with dementia. It is important to regularly ask about caregivers' needs and health. This is necessary because caregivers often need to be reminded to take care of themselves.

Slide 11:

- Shared decision-making is becoming an important part of dementia care in the clinic. Under these circumstances, the provider becomes the primary source of information for caregivers.

Providers have all the salient information readily available. You can refer caregivers to another member of the health care team or a trusted site on the internet for information.

Slide 12:

- It is time to recap Learning Objective #1: Establish partnerships with caregivers
- You are meeting for the first time with the daughter of an 82-year-old man recently diagnosed with moderate dementia.
- How will you go about forming a working relationship with this caregiver?
- Once you have formulated your answer, compare it to the response on the next slide.

Slide 13:

- Welcome her to your office and express your admiration for her taking on caregiving responsibilities.
- Discuss how you can work together.
  - She will help to coordinate care and be sure regimens are followed.
  - You will provide recommendations for care and discuss possible dementia medications.
  - Identify the best ways to communicate and discuss realistic response times to questions and concerns.
  - Discuss who needs to be involved in making decisions, including her father.
- Give her a general sense of what she can expect as her father's condition changes and when to reassess management decisions.
- Refer her to resources like the Alzheimer's Association and the local Area Agency on Aging.

Slide 14:

- Providers need to inform caregivers about the role of the Health Insurance Portability and Accountability Act, also known as HIPAA. Under this regulation, health care providers cannot release information unless the person living with dementia has signed a waiver for each caregiver or family member and the provider feels this is in everyone's best interest. Providers should discuss with the caregivers realistic response times to questions, given the constraints of workload and documentation requirements. Providers and caregivers need to determine how much can be addressed in a single session. This may include setting the agenda for next visits. When longer discussions are required, other team members, such as a social worker, may need to be involved. These team members need to be available when the caregivers present their concerns and they need adequate information and knowledge about the case.

Slide 15:

- A crucial step in establishing a partnership with caregivers is to assess their readiness for providing care. In some cases, the role may have been unplanned and the best that providers can do is to help caregivers adapt to their unforeseen position. In other instances, people may choose to take on the caregiving role. Here particularly, it is helpful to give caregivers a chance to decide how well equipped they are for the task. One potentially useful tool you can recommend is the Caregiver Self-Assessment Tool for assessing his/her level of preparedness. While this is not a formal assessment, it promotes discussion between you and the caregiver, prompts insights among potential caregivers, and helps current caregivers reassess their priorities and their actions.

Slide 16:

- The Caregiver Self-Assessment Tool is a self-administered tool that is designed to help potential caregivers contemplate their readiness to be a caregiver. This slide and the next one provide nine questions that address whether caregivers are prepared to take on the role. It will help caregivers review the pattern of their responses and discuss the answers with members of the health care team.

Slide 17:

- This slide shows the next set of questions and how to score the first 9 items. These 9 items address readiness to take on the caregiver role. If a prospective caregiver cannot answer yes to at least six of the items, you should counsel them to think carefully about becoming a caregiver. If they have no choice about becoming a caregiver, then your discussion should focus on what they must do in order to safely take on the role of caregiving.

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- Items 10, 11, and 12 consider ways a caregiver can get the support they need to continue in the caregiving role. The discussion should include ensuring that the caregiver has the needed support to be successful.

Slide 19:

- Questions 13 and 14 ask the caregiver to think about their caregiving experiences more broadly. The answers may not directly affect the final decision but are likely to influence the caregiving experience. There are no right or wrong answers. Rather, questions are designed to help potential caregivers consider what it means to take on the role. After completing the Caregiver Self-Assessment tool, caregivers should discuss their answers with you and other family members who may be affected by the caregiving decision. It is also important to note the tool can be used repeatedly as conditions for both the caregiver and the person living with dementia change. The next slide offers more ideas on how you can assess caregiver readiness.

Slide 20:

- The Family Care Alliance has suggested topics that primary care providers and other members of the health care team can also use to assess caregiver readiness. The topics include the cultural backgrounds of both the person living with dementia and the caregiver, and the expectations that both the family and the caregiver have about caregiving. It is important to assess the caregiver’s perception of his or her own health in order to assist you with addressing caregiver burden and stress. Other topics include caregiver’s values and preferences about caregiving and the toll that caregiving may take on their health. Finally, you should discuss resources, financial as well as emotional, that are available to support the caregiver.

Slide 21:

- Once caregiving has begun, members of the health care team need to support caregivers across the entire journey of dementia. With each change in the health status of the person living with dementia, the caregiver's role will also change. For example, caregiving tasks will move from providing supervision to providing direct care assistance with activities of daily living (which include dressing, eating, bathing, transferring and toileting). In addition, the health and well-being of the caregiver should be monitored throughout the course of the dementia. You need to periodically reevaluate, with caregivers, their ability to continue to provide care. A separate module will discuss your role in assuring the caregiver's health and well-being.

Slide 22:

- Health care providers need to be teachers. It takes time to teach caregivers what to do and how to do it. For example, a large survey conducted by the AARP found a common complaint from caregivers is a feeling of inadequacy around wound care and medications. Such areas need detailed, hands-on training. If you do not have the time to do such training, office or hospital personnel might be enlisted to help. Beyond simply giving advice and instruction, it's important to know that the instructions will be carried out. Ideally, caregivers must have an opportunity to demonstrate competency. If others are involved in the care, they also must be adequately trained. Finally, whenever possible, instructions should be written down for later review.

Slide 23:

- The ability of the person living with dementia to participate in decision-making will change and evolve as the dementia progresses. Caregivers will need to play an increasingly active role in day-to-day care when this happens. Providers will need to be proactive in updating care plans with persons living with dementia and their caregivers. With the progression of the dementia, the partnership will evolve to address an increased need for communication and more frequent assessment.

Slide 24:

- It is time to review Learning Objective #2: Discuss your responsibilities towards caregivers.
- Three months after the initial visit, you are meeting again with the daughter of the 82-year-old man who had recently been diagnosed with moderate dementia. Her father is preparing to move into her home three months from now.
- What new responsibilities do you have in this provider/caregiver partnership?
- After you have created your response, compare it to the one on the next slide.

Slide 25:

- Now that the decision has been made to become a full-time caregiver, the daughter will benefit from taking the Caregiver Self-Assessment Tool and discussing her answers with you. Encourage her to discuss her answers with other family members and caregivers as well. Ask about her concerns and remind her to include her father in as many discussions as possible, including getting him to express his preferences for care as the dementia progresses. Establish yourself as a reliable information source. Depending upon her father's overall health, she might need assistance with managing co-morbid conditions such as diabetes, heart disease, or depression. Because she is your patient, you will need to monitor her health and stress levels and make sure she understands the need to take care of her own health. If her father is also your patient, then, as her father's health changes, you will need to work together to update the care plan. You will need to remind her that her role as a caregiver will change as her father's health changes and that you can provide her with different resources, including information about respite end-of-life care.

Slide 26:

- Several screening tools are available to help members of the health care team assess caregiver burden and stress. These include the Zarit Burden Interview, Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Risk Appraisal, and Caregiver Reaction Scale. Websites are provided for each of these three tools. In addition, these and other resources on caregiving can be found on the last website listed. The links on this slide were last accessed on June 15, 2017.

Slide 27:

- Another assessment tool that focuses on stress and well-being is the Caregiver Well-Being Scale. It covers emotional needs, physical needs and self-security, and includes activities around self-care, connectedness, and time for self.

Slide 28:

- In order for health care providers to establish effective partnerships with caregivers, they need to communicate effectively, help potential caregivers decide if it is reasonable to take on or continue the caregiving role, and regularly assess the level of stress of caregiving on the caregiver.

Slide 29:

- This slide provides the full references for materials found in the module. The link on this slide was last accessed on June 15, 2017.

Slide 30:

- This and the following slide provide resources about interacting effectively with caregivers. The links on this slide were last accessed on June 15, 2017.

Slide 31:

- Note that in the Alzheimer's Tips and Tools the models are offered as examples; the specific details (e.g., contact information) are not relevant. The links on this slide were last accessed on June 15, 2017.

Slide 32:

- This slide provides hyperlinks to videos and websites on caregiver related issues. The links on this slide were last accessed on June 15, 2017.