

FACULTY GUIDE

Supplemental Module 2

**The Provider's Role in Shared Decision-Making with
Caregivers, Families, and Persons Living with Dementia**

May 2017

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Slide 1:

- The Provider's Role in Shared Decision Making with Caregivers, Families, and Persons Living with Dementia: This module is intended to make health care providers better able to participate in shared decision making with persons living with dementia and their caregivers.

Slide 2:

- At the end of this module, health care providers will be able to describe their central role in helping caregivers and persons living with dementia make good care decisions, ask caregiving questions that produce more effective conversations, and raise issues around risk aversion.

Slide 3:

- When working with persons living with dementia and their families and caregivers, a health provider will need to make a variety of decisions throughout the course of the patient's dementia. For example, how to manage the changing needs of the person living with dementia or how available finances and resources may affect care options. A provider may have to weigh the desire of the person living with dementia to remain at home with the needs of a caregiver who must cope with increasing responsibilities. Sometimes decisions have to be made in times of crisis. For example, how to best handle hospital discharge or transition across care settings; or which treatments to choose for acute and chronic illnesses, considering quality of care vs quality of life. Still other decisions address plans and preferences for care at the end of life including institutionalization; and when hospice or palliative care should be considered.

Slide 4:

- There are some basic principles about making these decisions. Ideally, decisions will be made using a shared decision strategy. In each instance, the decision-making should be shared between the person living with dementia, partners, caregivers and families, and other relevant parties including various members of the health care team. Different cultures may have different beliefs about who should participate in decision-making and caregiving. Health care providers should be sure that their efforts are consistent with the cultural mores of the patients, partners, families and caregivers.

Slide 5:

- Shared decision-making is a collaborative process that allows persons living with dementia, their families and their caregivers, and members of the health care team to make health decisions together, taking into account the best scientific evidence available, as well as the values and preferences of the person living with dementia. Shared decision-making honors both the expert knowledge of the health care providers and the right of the person living with dementia to be fully informed of all care options and their potential harms and benefits. This process provides persons living with dementia with the support they need to make the best individualized care decisions, while allowing health care providers to feel confident in the care they recommend. The internet link on this slide was last accessed on June 15, 2017.

Slide 6:

- In shared decision-making, members of the health care team, the person living with dementia and their caregivers, partners, and family members review objective information about the benefits and risks of different care options, including doing nothing. Ideally, a thoughtful decision about what is in the best interest of the person living with dementia would then result from this review. Health care providers can explain what the care options are, share information about the pros and cons of the different approaches, and evaluate the reliability and safety of the information that is being considered by the group.

Slide 7:

- The various members of the health care team play several roles in decision-making. They must determine decision-making capacity of persons living with dementia. Assessing capacity for shared decision-making includes determining whether the person living with dementia has the ability to understand information about treatment; the ability to appreciate how that information applies to his or her situation; the ability to reason with that information; and the ability to make a choice and express it. Health care providers are also sources of information. They need to verify that the caregiver, person living with dementia, partner, and family members have accurate knowledge of the prognosis and disease process so the provider can create a dialogue around realistic expectations. Health care providers often find themselves serving as facilitators or referees when discussions become contentious. In some cases this intercession may require trained care managers. It is the fundamental nature of the provider/patient relationship that the provider is a strong patient advocate. However, providers may occasionally find themselves in uncomfortable situations with some decision-making. For example, some treatment decisions may involve using the provider's skills and direct participation or the decisions may involve discharge plans that affect the institutions with which he or she is affiliated. If the provider feels there is a conflict of interest, then he or she should ensure that the person living with dementia has an unbiased advocate. That advocate might be another member of the same health care team. It is important to avoid even the appearance of bias.

Slide 8:

- Helping persons living with dementia make good decisions involves considering two basic elements: first, determining what the person living with dementia and the partners, family members, and caregivers hope to achieve, and second, deciding what is in the medical best interest of the person living with dementia. The challenge lies in finding the appropriate compromise between what the person living with dementia wants and what is in his/her best interest medically. It is always important to remember that these decisions may need to be reevaluated as the course of the dementia changes the needs and preferences of both the person living with dementia and the caregiver.

Slide 9:

- Now let's look at how well you can address Learning Objective #1: Describe your role in shared decision-making.

- An 82-year-old woman with advanced dementia sustains a hip fracture. What is the right treatment?
- How will you work with her to make a shared decision regarding her care?
- Once you have formulated your answer, go to the next slide to compare your response with the one presented there.

Slide 10:

- You need to call a meeting between all interested parties, which you, the primary care provider, will facilitate, along with an orthopedic surgeon to discuss the risks and benefits of treatment. During that meeting you need to make sure the following topics are discussed and resolved.
 - Are there other comorbidities that must be considered?
 - What was her ambulatory status prior to the fracture?
 - What is her current living situation? And would the decision differ if she has been living at home or in a Nursing Home?
 - What are the risks of anesthesia?
 - Will she be able to tolerate rehabilitation?
 - Once you describe these options and answer questions about the pros and cons of each of these suggested treatments, it is time to help the person living with dementia, caregiver, partner and family members decide upon the best course of action.

Slide 11:

- Health care providers may face some substantial barriers as they try to be actively involved in decision-making. It may be that not all members of the health care team have expertise in shared decision-making. All members of the health care team need to have the necessary information to discuss the implications of the decision, including the benefits and the harms of treatment options, the needs and preferences of the caregiver, and any fiscal constraints that exist.

Slide 12:

- The first step in good decision-making is setting the agenda of what you hope to accomplish during the shared decision making meeting. What is the fundamental question? Answering that question starts with defining what the needs and preferences of the person living with dementia are and what he or she, caregivers, partners and family members hope to achieve. Once the main question is determined it is critical to frame the question properly. Too often the question is posed in the context of an answer. For example “what is the best nursing home?” implies that moving to some nursing home is the answer; or “where should the patient have this operation?” implies that a decision has been made to have an operation. For many older people, especially those who are frail, as well as living with dementia, the more relevant question may involve deciding what action would make life most meaningful or satisfying. The overarching goal at the end of life may include forgoing treatment to pursue other goals.

Slide 13:

- Getting to that fundamental question can be hard. Health care providers can help families acknowledge the conflicts that make it difficult to identify the primary goal. For example there is

frequently a conflict between safety and autonomy. Providers need to recognize and make explicit the different perspectives that may arise. You must be prepared for old family histories and relationships to resurface. You should not neglect the perspective of the person living with dementia. Achieving some level of basic agreement may take more time (and perhaps even more training) than you may have. In such cases you may want to include a trained case manager in the decision making sessions (such as a social worker or psychologist who has experience working with families living with chronic illness, particularly dementia.).

Slide 14:

- There are several guidelines for organizing structured discussions. It is important to focus expressly on values and care preferences as part of the assessment process to facilitate mutual understanding of everyone's needs and preferences. These values of the person living with dementia should be obtained directly from him or her, not from a proxy or a surrogate, and should not be assumed. The discussion should address preferences for handling daily activities, such as finances and living arrangements well before the person living with dementia becomes unable to express his or her wishes, and certainly before a crisis arises. You should also support the active participation of the person living with dementia, caregivers, partners, and family members in developing the care plan. Keep in mind that persons living with dementia can often make decisions about care or state specific preferences for everyday activities even though they may be unable to answer seemingly simple questions about themselves. You need to recognize the caregiver's need for information, emotional support and practical help. Time constraints, sadness over loss, and stress of new and difficult tasks can be a great burden on the caregiver. It is important to determine what the person living with dementia wants and then balance the implications of those new roles and situations with the other work and responsibilities the caregiver must face. Also, do not assume that just one caregiver is involved. You must enter into discussions with caregivers, partners, and family members with an open mind. Take into account the wishes and preferences of the person living with dementia and the needs and the situation of the caregivers. You should encourage all family members and caregivers to recognize one another's rights to make their own life choices even if there may be disagreement about those choices. If a health or safety issue is an immediate risk, help the family members and caregivers to reach an agreement as quickly as possible.

Slide 15:

- When a person living with dementia develops other chronic conditions or an acute illness, decision-making becomes more difficult. Changes in comorbid conditions may warrant medical treatments that have serious side effects. For example, treatments for cancer, including surgery, chemotherapy and radiation, may be made more difficult by the presence of dementia. Because these treatment decisions are complicated, caregivers need to feel empowered to ask questions and to ask for other opinions. You cannot be expected have all the relevant facts on hand but you should be prepared to recommend additional information sources. If you send caregivers to the internet, you should have some feel for the quality of the information available from different sources. Empower caregivers and persons living with dementia to ask questions. Individuals in the early stage of dementia still have the ability to be part of the decisions around treatment even while still living with another chronic condition or an acute illness.

Slide 16:

- Let's now explore how well you can address Learning Objective #2: Frame caregiving questions effectively.
- You have convened a family meeting to discuss care options for a 79-year-old man with moderate dementia.
- How do you propose to begin the meeting? What kind of topics will you bring up?
- After you have composed your answer, compare it to the responses suggested on the next slide.

Slide 17:

- Start by getting everyone (beginning, of course, with the person living with dementia) to identify what their major goal is for the next several years for this gentleman living with **moderate** dementia. It may help to give some examples such as—having a comfortable life in familiar surroundings, being safe, living as long as possible.
- Use their responses to identify the level of basic agreement. For example, is there conflict between safety and other goals? If so, use the risk aversion tool to assess differences among participants; discuss the implications of those differences.
- Talk about the care options available and the benefits and risks of each.
 - If some individuals favor institutional care over home care, talk about what it will take to provide the two options.
 - Discuss caregiving as a communal task rather than falling on a single person. Who is willing to do what?
 - Identify supports to alleviate the burden of this caregiving
 - Discuss costs involved with different types of care, the likelihood of public funding, and the need for private funding.

Slide 18:

- As the dementia progresses, decisions about care and preferences will need to be reconsidered. Decisions that were applicable at one stage of dementia may no longer apply at a more advanced stage. Changes can occur in many areas, including in the health status of either the person living with dementia or the caregiver, or in their living arrangements, or in their financial resources. You should make sure that partners, families and caregivers understand why these decisions need to be reassessed. Then you should encourage them to revisit past decisions to determine if they are still appropriate.

Slide 19:

- Because the need to reassess past decisions is often precipitated by a change in status such as a hospitalization, health care providers need to be prepared to initiate new conversations with persons living with dementia, and their caregivers, partners, and families. There are several steps that can make this new decision-making process more effective. During a crisis you must be vigilant about ensuring that the caregiver, partner, and family members understand why decision making is critical and immediate. You should constantly assess the perceptions of the person living with dementia and the caregiver, partner, and family members and evaluate their receptiveness to receive new information. Do they want it at that moment? Would they prefer

receiving it in steps, with follow-up? You should determine how to provide knowledge to the caregiver, partner, family members, and the person with dementia. You need to address the emotions of all involved with empathy. The slide has two URL links that contain for some practical tips on how to carry out these care conversations. The internet links on this slide were last accessed on June 15, 2017.

Slide 20:

- An excellent place for you to start learning about the care preferences and values of the person living with dementia, caregiver, partner, and family members is with discussions on advance care planning. Advance care planning refers to the whole process of reflection, learning, and discussion with others, as well as the creation of an advance care directive. Although often a difficult topic, it is an important component of overall care planning for dementia. Having several discussions on this topic provides knowledge about preferences that can be put to good use during a status change when shared decision-making discussions are reopened to address new circumstances.

Slide 21:

- Dementia care involves making decisions about how much medical and/or life-sustaining care should be given. These decisions will need to be continuously reviewed as the dementia progresses but discussions should start early, if only as a rehearsal. Here again the person living with dementia should be at the center of decision-making for as long as possible. A health care proxy is a legal document in which a person living with dementia appoints an advocate to legally make health care decisions on his or her behalf, when he or she is incapable of making and executing the health care decisions stipulated in the proxy. A number of tools are available for health care proxy decision-making. They include advance directives, physician orders for life-sustaining treatments, medical orders for life-sustaining treatments, living wills and durable power of attorney. Most forms are specific to the state the person living with dementia is in so families, partners, and caregivers should be directed to the correct state form.

Slide 22:

- Working with the person living with dementia, caregiver, partner, and family members on advance directives is good practice for making decisions in a more rapid timeframe, such as at the time of discharge from the hospital. Many important care decisions occur quickly at the time of discharge from the hospital. The event that led to the hospitalization may have changed the clinical status of the person living with dementia, and thus new care options may be needed. Although decisions at the time of hospital discharge planning may have serious effects on the rest of the person's life, the conditions for making this momentous decision are often less than ideal. A hospital discharge planner is charged with facilitating a safe and appropriate discharge but is not an advocate for the person living with dementia. You need to decide if you can be an unbiased advocate for the person living with dementia. If not, you may want to suggest someone else on your health care team who can fill the role of patient advocate. Having participated in the development and reassessment of the care plan and knowing the values and preferences of person living with dementia, the caregiver, partner, and family members makes you the best candidate to assign such an advocate.

Slide 23:

- Many health care providers participate in discharge planning including physicians, nurses, social workers, case managers, and patient navigators. When participating in the hospital discharge process, providers should think of it as a two-step process. The first step consists of deciding what type of available and affordable care is most likely to achieve the prime goals of the person living with dementia, the caregiver, the partner, and the family. The second step addresses identifying the best vendor to provide the desired service. This distinction is important because the criteria for each step are different.

Slide 24:

- There are several criteria that you might wish to share with caregivers, partners, family, members, and persons living with dementia, for deciding what type of care will achieve the primary outcomes. These include: What is the desired primary outcome? What are realistic goals of care? What risks are caregivers, partners, families, and persons living with dementia willing to accept? How does that level of risk tolerance agree with the preferences of the person living with dementia? What care options are available? How well can each option achieve the desired outcomes and minimize the risks? Which options are realistic? (This would include issues about immediate accessibility.) What costs are involved in each option? Which options will third-party payers cover? There are some other factors to consider as well. Where is care currently being provided? If the person living with dementia has been cared for at home, who is providing that care? Is it feasible to mobilize friends and family to assist with care? Cultural considerations of care include diverse views, goals of such care, family structures, and what is acceptable for both the caregiver and the person living with dementia.

Slide 25:

- Because caregivers, partners, family members, and persons living with dementia may vary widely in their tolerance for risk, it is often difficult to reach a decision on how best to change care. Risk aversion refers to people's reluctance to let a person living with dementia to engage in any activity that might lead to some harm, even if they want to do it. You can help them take the first step in addressing these differences by making their differences of opinion more explicit. You can do this by asking each caregiver, partner, family member, and person living with dementia to complete the Risk Aversion Assessment Tool, a simple assessment of their tolerance for taking risks. These questions are designed to provoke discussion. All members of the health care team should encourage each family member to share his/her answers to uncover the different levels of willingness to allow persons living with dementia take risks that need to be resolved in order to allow a decision to be made. This will help all of you give better advice in times of decision making.

Slide 26:

- This slide shows the 10-item risk aversion assessment tool. Each question can be answered yes or no. The goal is not to create a score but rather to discuss the individual items. The answers provided by the person living with dementia, the caregiver, the partner, and the family

members will allow you to better understand which care options are more likely to be acceptable to each group.

Slide 27:

- Let us now see how at ease you are with Learning Objective #3: Feel comfortable raising issues around risk aversion.
- You are convening a meeting to plan care for an 87-year-old man with moderate dementia. There is clear disagreement about risk tolerance. The person living with dementia wants to stay home even if it means he may fall or cause an accident. One son agrees; one daughter disagrees strongly and wants him safe at all costs.
- How do you propose to lead this discussion concerning differences of opinion on risk tolerance? Once you have your answer, compare it to the response listed on the next slide.

Slide 28:

- Begin the meeting by acknowledging the conflict. Suggest that everyone complete the risk aversion assessment tool.
- Once everyone has done so, discuss everyone's responses. You should look for areas of agreement but realize there will not likely be consensus initially.
- Get those who favor more risk to acknowledge that risk in concrete terms.
- Get those who want safety to acknowledge the constraints that this makes for the person living with dementia.
- Be an advocate for the person living with dementia; his values should count substantially and your expert opinion of how realistic his preference is will help everyone reach consensus.
- Recognize that if one child becomes the caregiver, he or she will bear the brunt of an untoward event.
- Be sure the rest of those present take responsibility for bad outcomes as well.

Slide 29:

- When Step 1 has determined that a different level of care is needed, then it is time for a new set of questions in Step 2: Choosing a new provider. Again, members of the health care team can promote this discussion by suggesting multiple questions for consideration. For example: If the person living with dementia is to return home, are there new services that can be introduced in the home? If a homecare agency is selected, does it have a staff with a full array of therapists or policies about weekend care? If a nursing home or assisted living site is the type of care targeted, is it convenient to the family members, partner, and caregivers and is it somewhere the person with dementia would want to live? Will there be sufficient privacy? Does it have a philosophy compatible with the person living with dementia's philosophy? Is there any religious or ethnic overlay? Staff training is important: does the staff (of any agency or facility) receive training regarding dementia disorders and are the direct care staff rewarded for providing high quality care? What is the facility/agency culture – is it person centered? How do they work with interested parties? If the person living with dementia has special needs, for example for caregivers who speak a particular language, will the agency find such a resource? What does it cost? This should be expressed in terms of the total cost but also the net cost after third party payers cover their share.

Slide 30:

- It is important to realize that discharge planning takes time. It takes time to determine the overarching goal of the person living with dementia and his/her family, partner, and caregiver. In some cases family members may need to assemble from different parts of the country to resolve conflicts. Identifying the best type of care involves determining the primary goal and this may not happen quickly. Identifying the best vendor for the new care means getting information about the quality of care available but also about the availability of care in general. If a nursing home or an assisted living site is the type of care chosen, substantial time may be required to allow all interested parties to visit potential sites. Ideally discharge planning will start soon after admission to the hospital, although the patient's clinical course may not be clear then. By including all members of the health care team in the process as soon as possible, a more informed choice can be made.

Slide 31:

- Other factors may influence decisions across the dementia timeline and the care spectrum. Many persons living with dementia worry about how end-of-life decisions will create burdens for the family. These might include legal issues such as durable power of attorney, quality of care issues, suffering and financial worries. These issues play into many decisions about finding community resources, such as homecare, adult day care and nursing homes. These resources listed here provide more information on these subjects and on how to do the necessary planning. The internet links on this slide were last accessed on June 15, 2017.

Slide 32:

- Dementia is a terminal illness. There may come a time when the person living with dementia is experiencing a decline in functional status that is not responding to current levels of care. Or the management of co-morbid conditions may be complicating the dementia care or may be complicated by the presence of the dementia. At this time, consider introducing the topic of palliative and hospice care to caregivers and families. Many families and caregivers view palliative care and hospice care as a failure or a decision to give up. As a result, these two topics may require multiple discussions and careful explanations of when palliative care and hospice care are appropriate, and how they differ.

Slide 33:

- Palliative care decisions require decision-making conversations. Palliative care is given in addition to regular dementia care. It helps to relieve pain and stress so that the person living with dementia, the family, and the caregiver can have the best possible quality of life. Palliative care affirms life by supporting the care plans and goals of the person living with dementia, including their hopes for life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. It allows for the addition of more supportive services such as pain control, nutrition education and supplementation, and visits from a chaplain and a social worker. It emphasizes making patients as comfortable as possible, a philosophy consistent with good dementia care.

Slide 34:

- The differences between palliative and hospice care are often subtle to those who are not clinically trained so you should be prepared to educate caregivers and families about those differences and to provide guidance on which type of care is more appropriate for the person living with dementia. Hospice care is provided during the final 6 months of a person's life and provides medical care, pain management, and emotional and spiritual support for the person living with dementia and to the family and caregivers, as well. It should be noted that the decision to enter hospice can be rescinded if the person's health status improves. Hospice also provides bereavement care and counseling to surviving family member, partner, and friends. Hospice care is covered under Medicare and is a benefit that may be appropriate for many persons living with dementia, especially during the late stages. Referral to a hospice implies a change in the goals of care but makes available a set of supportive services that might not otherwise be available. Whether you or the caregiver or family bring up conversations about hospice first, you must be prepared to discuss the pros and cons for hospice care and respectfully address the concerns and wishes of the caregiver or family.

Slide 35:

- In conclusion, shared decision-making is important but often hard to achieve, either due to lack of consensus among the parties involved, or due to the lack of time to gather all the information ideally needed to make decisions. You and the other providers on your care team need to help caregivers, families, partners, and persons living with dementia make thoughtful but timely decisions. You need to present questions in terms of quality of life goals, not just risks and benefits of alternative treatments. Decisions are best made using a structured approach.

Slide 36:

- This slide contains the full references of material mentioned in the module. The internet links on this slide were last accessed on June 15, 2017.

Slide 37:

- The URL link on this page takes the user to a series of videoconferences on Palliative Care in End Stage Dementia that was supported by HRSA grant number UB4HP26039 to Rowan University 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). The other links are to Alzheimer's Association resources for persons living with dementia and caregivers. The internet links on this slide were last accessed on June 15, 2017.