

FACULTY GUIDE

Supplemental Module 2

**The Caregiver Role in Shared Decision-Making with Persons
Living with Dementia**

December 2017

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Module 2: The Caregiver Role in Shared Decision-Making with Persons Living with Dementia

Slide 1:

We designed this presentation to help you think about decisions that you will have to make along with persons living with dementia. This is the second of five presentations designed to help you better understand tasks you'll undertake when caring for a person living with dementia.

Slide 2:

By the end of this module you will learn how shared decision-making helps improve the care of a person living with dementia, know what decisions need to be made before a person living with dementia is released from a hospital, and know five different approaches to long-term care for persons living with dementia after they have left the hospital.

Slide 4:

Shared decision-making is a joint process that allows persons living with dementia, their caregivers and other interested parties, and the health care team to make health care decisions together, taking into account the best medical advice, as well as the wishes of the person living with dementia. It helps persons living with dementia make the best decisions, and gives health care providers faith in the care they suggest. This process may take several days, and in some cases even weeks. An explanation of shared decision making can be found at https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf.

Slide 5:

Persons living with dementia should share decision-making with all caregivers and members of the health care team. The health care team provides information about the pros and cons of possible treatments, and the person living with dementia and the caregivers decide on a course of action after considering these facts. Whenever possible, the person living with dementia should play a central role in making decisions. The process takes time, and decisions may take several days, and in some cases even weeks. As the dementia progresses, decisions need to be reviewed and possibly changed, as appropriate.

Some decisions will be made daily. While other decisions will be made during times of crisis. A particularly difficult time for decision-making is at the end of a hospital stay. You will have to decide if the person living with dementia can continue to be cared for at home and what services and supports may be required; or if end-of-life care may have to be arranged.

Slide 6:

There are some guidelines that will help families make decisions.

- First, persons living with dementia need to make their wishes known. They are often able to express their wishes, and make decisions through many of the stages of dementia. Maybe they wish to have the longest life possible; or the best quality of life; or to be safe; or to make the caregiver's life easier.

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- Second, the group should discuss those wishes. Some may care about safety, while others may care about independence. These ideas may change as the dementia progresses. Discussions should acknowledge everyone's preferences for handling daily tasks, such as paying bills and doing housework.
- If people disagree about how to do something, they should do so respectfully. Sometimes, the wishes of the person living with dementia are not acknowledged. Or, past grievances may need to be resolved first. All of these things make decision-making difficult and sometimes, it may be helpful to use an outside care manager or other individual to assist with the process.

Slide 7:

As dementia advances, you, and the person living with dementia, must rethink past decisions. What works at one stage of dementia may not work at a later stage.

- Certain behaviors can warn you that there is a need for change. These behaviors include wandering, hitting or biting, and loss of bowel control.
- You should also concentrate on reducing any stress you feel, as things change. This might include getting extra help from other family members or paid helpers.
- Other diseases (e.g. cancer) or medical procedures (e.g. surgery), may require treatments that cause serious side effects.
- Dementia can make those side effects worse. Seek out second and third opinions, and/or inquire about recent research or other information in these situations.

Slide 8:

Changes to care should follow wishes that the person living with dementia gave while still healthy. Those wishes should include final decisions about life support and other end-of-life care. You can find many tools on the internet or from a lawyer to help document advance care planning wishes. These include advance directives, physician orders for life- saving treatments or medical orders for life- saving treatments, living wills, and durable power of attorney. A care manager or a lawyer can help a caregiver with these documents. Advance care planning makes decision-making easier when getting out of the hospital.

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Making the best decision depends on getting good information.

The healthcare team is the first stop for that information.

Other reliable sources of information include the Alzheimer's Association, the Alzheimer's Disease Education & Referral Center (ADEAR) run by the National Institute on Aging, the Administration on Aging/Aging and Disability Network (<https://www.acl.gov/programs>), the Centers for Medicare & Medicaid Services Home & Community Based Services (<https://www.medicaid.gov/medicaid/hcbs/index.html>) and Eldercare locator <https://www.usa.gov/federal-agencies/eldercare-locator>

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Slide 11:

Leaving the hospital requires a doctor's order.

- The discharge planner coordinates the release.
 - When the plan is for the person living with dementia to go to a nursing home, the discharge planner identifies available openings.
- For those paying privately, hiring a care manager to talk to the discharge planner might be helpful.

Slide 12:

A stay in a hospital is not easy for a person living with dementia but release from hospital is even more complicated.

- Decisions must be made quickly about care and living arrangements.
 - The event that led to the hospital stay, and the hospital stay itself, may have changed the health of the person living with dementia.
- You should start working right away with a hospital discharge planner and interdisciplinary medical care team to make sure the transition from the hospital to home or another facility is seamless, and in line with the patient's wishes.
- Releasing someone safely from the hospital must include two primary determinations:
 1. What care the person living with dementia will now require
 2. Finding care that is available and affordable.

If the person living with dementia is returning home, caregivers and discharge planners may need to arrange for new help.

If the choice is to go to a nursing home or assisted living, caregivers and/or family members may need to visit possible sites to determine if the site meets the needs and preferences of the person living with dementia.

Slide 13:

There are many issues to consider before discharging a patient.

- Is the care that was being provided before hospitalization enough? Or is more, or different, care required after the hospital stay?
- What are the options, and are they affordable?
- Which care facilities have openings?
- Will insurance cover some options?

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- Should you choose another facility while you are on the waiting list for your first choice?

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If you determine long-term care to be the best option, but need help determining which type fits best, use the website provided.

Slide 16:

Home health care is a Medicare service supervised by registered nurses and provides active nursing care. Staff also include physical, occupational, and speech therapists; and social workers.

Home health aides provide most of the care, which typically focuses on helping the person released from the hospital to regain strength and learn tasks needed to allow them to live safely at home.

Slide 17:

Personal care is a service that helps persons living with dementia meet their basic care needs at home.

Personal care aides or homemakers provide most of this care under the supervision of nurses. In many cases, people buy this care by hiring aides directly.

Medicare does not cover personal care, but Medicaid may cover it for certain people.

Slide 18:

Rehabilitation units are licensed facilities that can provide rehabilitation. They are usually separate units of a hospital.

- A specialist physician, called a physiatrist, supervises the care typically provided by nurses, physical therapists, occupational therapists and speech therapists.
- Aides may carry out the most routine care.
- To be eligible for coverage by Medicare, patients must receive at least three hours of therapy each day from a physical therapist, an occupational therapist or a speech therapist.

Slide 19:

Daycare or adult day health center care is provided outside the home each day. These facilities may provide socialization for older persons otherwise confined to their homes; and offer relief to caregivers.

Some daycare programs provide:

- organized activities;
- assistance with daily living needs, including bathing;
- medical or nursing services.

Some Medicaid programs may help pay for Adult Day Health care as home and community-based services.

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Slide 20:

Assisted living is a type of care where residents live as tenants in self-contained units that include living quarters, a private bathroom, and cooking and food storage facilities. They may use a common dining room and participate in various organized activities, but they have their own routines and can decide who enters their living space.

Usually, assisted living provides less nursing care and less active involvement in treatment. An assisted-living facility may refuse to care for a person whose condition deteriorates to a point where they cannot provide the appropriate amount or level of care.

Most assisted-living care is paid for privately. Medicaid may pay for assisted living care for some people participating in home and community-based services programs, depending on the state.

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The nursing home is the most widely known form of long-term care. Licensed to provide long-term care funded either privately, or through Medicaid; nursing homes may also provide shorter term, post-hospital care paid for under Medicare.

- Nursing homes are required to provide certain levels of nursing staff who can care for frail residents.
- Some nursing homes have special units for persons living with dementia.

Slide 22:

Hospice care relieves uncomfortable symptoms like pain, nausea, constipation, and itching, and provides the emotional supports needed to face death. Usually provided at home, hospice care is a Medicare benefit for those who are expected to live less than six months. In choosing a hospice program, the person living with dementia decides to stop traditional care to make the end-of-life as peaceful and stress-free as possible. If the person's health improves, they can leave hospice and return later.

Slide 24:

When considering home care options, there are several questions you may want to ask to determine if a particular type of home care, or a particular facility will be best for the person living with dementia's situation:

- Does the company have different kinds of therapists?
- Do they work weekends?
- If the person living with dementia has a special need, such as a caregiver who speaks a specific language, will the agency help?
- It is important to know how they determine costs. And what will insurance cover, if anything, of that cost?

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We provide questions you should ask when considering either a nursing home or an assisted living facility in our presentations:

- What to Consider When Choosing a Nursing Home
- What to Consider When Choosing an Assisted Living Facility

Slide 26:

In conclusion, decision-making happens throughout the course of the dementia care.

Decisions, once made, may need to be re-evaluated as the health of the person living with dementia changes or the caregiver's circumstances change.

Using a shared decision-making approach that includes the person living with dementia, caregivers, partners, family members, and the members of the health care team will make sure everyone understands difficult decisions. It requires sharing information about wishes, options and likely results.

You should ask questions and seek second and third opinions. If you go to the internet, avoid sites sponsored by organizations that sell products or services.

Good decision-making takes time and effort.