

**FACULTY GUIDE**  
**Supplemental Module 1**  
**Welcome to Caregiving**

**December 2017**

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## Module 1: Welcome to Caregiving

### Slide 1:

Welcome to Caregiving for Persons Living with Dementia: This presentation intends to help you—a caregiver, or care partner—think about some of the issues around caregiving for persons living with dementia. We developed this presentation under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The Department of Health and Human Services, Office of Women’s Health, funded this work.

To help you better understand the needs of a person living with dementia, we developed five distinct presentations:

- Caregiver roles,
- Shared decision-making,
- Communicating with health care providers,
- Caregiver self-care, and
- Dealing with difficult behaviors of dementia.

In addition, there are four presentations to address the same topics as above, but from the point of view of the medical providers on the healthcare team.

### Slide 2:

We will present you with what you should know before becoming a caregiver. Specifically, we’d review:

- what a caregiver does;
- the many roles & associated duties of a caregiver; and
- why you should take care of yourself too.

### Slide 4:

As a caregiver, you may be a friend, family member, partner or neighbor.

Caregiving covers a broad range of mostly unpaid help with multiple kinds of health-related activities and includes mental, physical, emotional and other types of support. The care may be daily or occasional, and may be of short or long duration.

You assist in basic personal care activities such as eating and bathing; household chores such as shopping and meal preparation, and other activities such as managing medications, attending doctors’ visits, and handling insurance and paying bills. You may also be involved in managing health care and assistive technology activities at home, and in helping the person living with dementia move safely between settings of care.

### Slide 5:

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You should be valued for all you do to improve the lives of persons living with dementia. Because of your efforts as a caregiver, many persons living with dementia are able to live in the community longer.

You serve as the link between those giving paid medical care and the person living with dementia.

Although caregiving for persons living with dementia is hard work, it can be rewarding.

You may find that

- the experience provides a sense of personal joy and a chance to give back;
- it allows you time to share family history and can offer a sense of closure;
- it provides you with a model for respect and personal courage; and/or
- caring for a loved one gives you a lasting sense of purpose and meaning.

### Slide 6:

There are some basic rules about caregiving to keep in mind:

- Caregiving can last a long time and it is hard work.
- If you, the caregiver, take care of yourself and remain healthy, you can provide help for longer.
- Sharing caregiving responsibilities with others, including through paid assistance, helps you stay healthy.

### Slide 7:

The diagnosis of dementia is a call-to-action. It is a time for you, as a caregiver for the person living with dementia, to make a care plan based on information from health care and community-based providers about expectations, requirements for care, and available resources and services in the community.

You should work with all other caregivers of the person living with dementia to discuss needs and share caregiving tasks.

**EXAMPLE:** If someone already lives with the person living with dementia then that person may likely become the main caregiver.

However, you may need another plan if that individual is not well either.

### Slide 8:

It is important to prepare and gather all of the information necessary to organize care.

Because of privacy laws, you will need permission from the person living with dementia to access their health, financial, personal and legal records; keep in mind and respect their health care wishes and preferences. You will also need to keep updated lists about medical conditions, medications, allergies, doctors and other health providers of the person living with dementia.

### Slide 9:

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Create a list—similar to this one—of financial, health, and personal information. Keep it in a safe location – perhaps written in a notebook or typed into a computer, cell phone or tablet.

### Slide 10:

The caregiving role changes as dementia progresses.

As early as possible, be sure to ask the person for whom you are caring about their wishes for care when they can no longer speak for themselves. These are called their advance directives.

### Stages of Dementia

In the early stages of dementia, you may have to give a few reminders on how to do things, and only occasionally help with harder tasks.

At the level of mild mental decline, you may deal with frustration and depression; you may have to make doctors' appointments; and you may have to help them leave a job or retire.

With moderate mental decline you may see more behavioral challenges and may need to help with tasks such as shopping, housework, bill paying, providing or assisting with transportation, giving medications, using the telephone and technology, and caring for pets.

### Slide 11:

The disease may then progress to a moderately severe level of cognitive decline.

At this stage, you may need to provide more assistance with dressing and bathing. There may be problems with nighttime sleep. You may need to figure out how to address more severe behavioral challenges. You may need to arrange for paid help. You and other caregivers may need to talk about what to do if the person living with dementia becomes physically ill.

If the person progresses into severe cognitive decline, you may have to help with most daily tasks. At this point you should begin to think about whether the person needs more caregivers.

Finally, if the person reaches the stage of very severe cognitive decline, you may need to help with almost everything; and end-of-life care decisions will need to be put into place.

### Slide 13:

Over time, you will play multiple roles in providing care to the person living with dementia.

### Roles Include

- Care providers – those providing direct care to the person living with dementia
- Care coordinators – those who make certain the person living with dementia receives appropriate care
- As the primary resource with important information about medical conditions and financial issues
  - For some tasks, such as bill paying, you will need to use a lawyer to secure durable power of financial affairs certification or become a legal guardian.

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- Advocates – ensure the person gets the best care they can; provide emotional support and encouragement to persons living with dementia as their abilities decline.

### Slide 14:

Caregiving tasks include household chores such as cooking meals, making appointments, paying bills, and dispensing medicines; and, as the dementia progresses, outside activities like driving and shopping. You may need to remind persons living with dementia what they need to do in order to perform various tasks.

Eventually, as the dementia continues, you may also need to assist with daily tasks such as bathing, getting out of bed, dressing, using the toilet, and eating.

At some point, you may also have to manage difficult behaviors such as wandering, aggression and agitation. It may be helpful to find services such as daycare, respite care, transportation help and home delivered meals to alleviate some of the workload.

### Slide 15:

Care coordinators and care managers are responsible for keeping records and appointments, and requesting help to provide the best care. The care coordinator role becomes more important with the addition of more helpers and the need to keep everyone informed about the care plan and duties.

You might want to consider hiring a paid care manager to serve as the link between the caregiver and the health care system. A local Area Agency on Aging, a managed care plan, a private pay agency, or another caregiver may be able to recommend a care manager.

### Slide 16:

You serve as an important information resource for health providers, keeping track of prescribed medications to help providers prevent drug duplication and interactions. Often, you'll also have to navigate insurance coverage, Medicare, Medicaid, or private insurance on behalf of the person living with dementia, including handling complex forms and bill paying.

Unsurprisingly, as dementia progresses, your role as an information resource may also become more complicated.

### Slide 17:

A person living with dementia may ask you to become an advocate, a difficult but important job.

Advocates remind health care providers what the wishes and preferences of the person living with dementia are throughout the dementia journey.

Advocacy is especially important in end-of-life care decisions. Your caregiving does not end when the person living with dementia enters a hospital, nursing home, or assisted living facility. It is important to look for problems and address them in these group settings.

### Slide 18:

You provide important emotional support and comfort to the person living with dementia.

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You can help persons living with dementia cope with their challenges and decreasing abilities by keeping them active and engaged by breaking down activities into manageable tasks.

### Slide 20:

You do not always have a choice about becoming a caregiver. However, caregiving does not come naturally to everyone. Personality and circumstances may affect your caregiving role. Taking on caregiving deserves consideration since the job is difficult. Giving care is not always an all-or-nothing choice. Some people may be able to take on all of the caregiving responsibilities, while others can take on part of the work; both types of commitments will require outside help.

The Caregiver Readiness Tool helps you easily determine if you're ready to become a caregiver. You can find the Caregiver Readiness Tool in the bonus talk called, "*Are You Ready to Be a Caregiver?*" Thinking about your answers to the questions will help you decide how much of the caregiving role you can realistically assume and how much of it you need to share with others. Additional resources include The Caregiver Assessment Tool and the Caregiver Briefcase.

### Slide 21:

This and the next slide pose nine key questions about caregiver readiness. People interested in becoming caregivers should be able to answer positively to at least six of these questions. Negative answers show areas where more planning is necessary. Sometimes the caregiver role you are able to take on is different from the role you want to take on.

### Slide 22:

This slide shows questions 6 through 9. A positive response to all nine questions indicates that you are ready to begin caregiving. A yes to less than six of the nine questions suggests that more work is necessary to prepare for caregiving. In some cases, even a single "no" may mean that caregiving is not a good idea without more planning and help.

### Slide 23:

Items 10, 11 and 12 of the Caregiver Readiness Tool will help you think about the support you need to improve your caregiving.

### Slide 24:

The last two items, numbers 13 and 14, show some things to think about before becoming a caregiver. Your answers will help you predict the effect that caregiving will have on your life.

Now think about your answers. This is not a quiz; there are no right or wrong responses. The tool helps you determine how caregiving will affect you. "Yes" answers to the first nine questions show that you are ready to be a caregiver. If you answer "no" to three or more items, consider getting help with caregiving responsibilities. Items 10 to 12 demonstrate ways of getting that help. Items 13 and 14 look at long-term effects of caregiving. The Alzheimer's Association or your local Area Agency on Aging have good resources and advice about assistance options.

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Think carefully before taking on a caregiving role. Although not everyone is a natural caregiver, the Caregiver Readiness Tool can help you determine which role best suits you. You can also use the tool to identify how others can contribute to caregiving.

### **Slide 26:**

Finally, an important part of being a good caregiver is taking care of your own mental and physical health. Caregiver health is so important that there is a separate talk in this series about how caregivers can take better care of themselves called “Caregiver Self-Care”. Depression is usually the first feeling that is noticeable. But emotions ranging from anxiety and worry about the future to anger, frustration, and guilt can also be present, sometimes leading to substance abuse. Be sure to talk to your own doctor about your health.

### **Slide 27:**

In conclusion, caregiving is critical to dementia care. Caregivers will play many different kinds of roles across the dementia journey and they give that care no matter where a person living with dementia lives. Finally, you should keep in mind that staying healthy yourself allows you to take better care of the person living with dementia.