

FACULTY GUIDE

Supplemental Module 4

Caregiver Self-Care

December 2017

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Module 4: Caregiver Self-Care

Slide 1:

Caregiver Self-Care: This talk discusses things that caregivers can do to protect their own health. It is one of a series of talks that was developed under a contract from the Health Resources and Services Administration of the Department of Health and Human Services. This work was funded by the Department of Health and Human Services, Office of Women's Health.

Slide 2:

This presentation aims to help you understand how the stress of caregiving affects your health and well-being; and how to find respite and other key resources to help you protect your health.

Slide 3:

Caregivers who provide care for someone at home experience caregiver stress.

This stress may be physical, as you become worn down from the physical nature of the work. Or it can be emotional as you watch someone's health decline. It can be money-related or it can be social as the lack of time and energy prevents them from seeing friends and family. It can be any one or all of these things at the same time. It is not surprising that caregivers of persons living with dementia have more stress than caregivers who care for people without memory loss.

A number of symptoms are related to stress. They include feeling overwhelmed or alone, having trouble sleeping, and losing your temper. You may struggle with keeping your weight stable. You may be worried or sad.

You need to know that these symptoms can affect your health.

- For example, caregiving for someone living with dementia may leave you with no time to focus on a proper diet or to get any exercise. As a result, you may not eat right and you may gain weight or feel more tired, resulting in less energy for caregiving.

Slide 4:

Caring for yourself is one of the most important, and one of the most often forgotten things you can do as a caregiver. When your needs are met, the person you care for will benefit, too. Caregiving takes stamina. Taking care of yourself helps you take better care of others.

Remind yourself that you are doing the best you can and give yourself credit for the care you provide. You cannot do everything perfectly and trying to do so will only add to your stress.

Two things to consider about self-care

- many people who become caregivers have existing physical and/or mental health problems that can get worse if they are neglected, and
- new health problems can develop as a result of the caregiving.

The next few slides will present tips for helping you take better care of yourself while providing care.

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Slide 5:

Early signs such as anger, tiredness, unplanned weight change, and trouble sleeping warn you that you are under stress. Sources of that stress could be your work schedule, difficult personal relationships, major life changes, money troubles, and worry.

Recognizing the sources of the stress will make you better able to decide what you can and cannot change. Taking action to reduce stress can give you a sense of control.

You can do something fun like walking, gardening, meditating or meeting with a friend or family. If finding enough time is a problem, take more, shorter breaks. Also pay attention to your diet, especially if you eat while under stress. To get at least six to eight hours of sleep a day, you may need to take naps during the day. Find a spiritual outlet that gives you a sense of purpose, meaning, and connection such as meditation or prayer. You may find that talking with a clinical psychologist who specializes in dementia will bring peace. You may also consider joining a support group for caregivers of persons living with dementia. They can provide both support and practical advice.

Slide 6:

A regular check-up is an important first step in maintaining your health. Tell your provider that you are a caregiver and talk about your stress. Talk about how your caregiving is affecting you physically, emotionally, and mentally and share any financial concerns you may have. Talk about episodes of depression, anger, frustration, anxiety or sickness you may have experienced.

As you witness the health of the person living with dementia decline, you may feel grief and loss. Social workers and clinical psychologists can help you deal with all of these emotions. Set personal goals that support a healthy lifestyle and include good nutrition, exercise, adequate sleep, and a social support network.

Slide 7:

Caregiving is easier when the work is shared, but asking for help is not easy.

Create a list of caregiving tasks and list of volunteers who have offered to help in the past. Then assign tasks to individuals based on their interest and availability.

Because caregiving is exhausting, consider using respite care. Respite care allows a caregiver to take time off from caregiving responsibilities and return well-rested and better able to cope with the stress of the work. Respite care can be provided inside or outside the home and range from a few hours to several days. As the dementia progresses and caregiving increases, your need for respite will likely increase also. Ideally, you can use respite time to relax and re-energize.

However, you may have other responsibilities such as housework, your job, or other personal appointments. You may find it useful to spend the time reorganizing so you feel more in control. It doesn't matter what you do as long as you take a break from caregiving.

Slide 8:

There are several types of respite care.

- In-home respite can be provided by a family member or a friend.

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- There are also home care agencies that provide personal care aides who can supervise persons living with dementia or provide direct care, freeing you up to attend to personal needs.
- Out-of-home respite includes adult day programs where the person living with dementia is brought to therapeutic activities for a few hours or even an entire day.
 - Emergency respite can also be found at many of these homecare agencies, adult day care, health centers, and residential care facilities that can provide overnight (or longer) respite care.
 - Using each of these agencies in non-emergency situations will allow you to “test-drive” the services and identify one or two for emergency purposes.
 - You can get referrals from your local Area Agency on Aging, the Alzheimer’s Association, or by dialing 2-1-1, the nationwide resource and information helpline.

Slide 9:

Respite care is usually not free. There may be insurance coverage for some types of respite care.

Depending on the state, Medicaid may support respite care for people enrolled in that program. The only way to get coverage under Medicare is if the person living with dementia is enrolled in a hospice program that provides respite care.

Most homecare agencies provide Social Security and Workmen's Compensation coverage for their home help staff. If you are not eligible to receive these kinds of respite services, you may need to pay for respite care yourself. If you hire the help yourself, you may need to arrange for this coverage.

Your local Area Agency on Aging office should be able to advise you on how to make these arrangements.

Slide 10:

By relieving stress and taking care of yourself, you can better support someone living with dementia.

There are a number of resources and tips to help you manage caregiver stress.

- HHS’s Office on Women’s Health suggests taking community-based classes to learn how to better understand illnesses.
- Take advantage of offers to help.
- Join a support group for caregivers recommended by your local chapter of the Alzheimer’s Association.
- Stay in touch with family and friends and do things that you enjoy.
- A key component of caregiver self-care is a healthy lifestyle. Exercising as often as possible, even moderately, eating healthy, and getting enough sleep are important.
- Finally, you should make sure to tell your provider that you are a caregiver and talk about depression and stress.

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Slide 11:

An important part of achieving better self-care is finding services and supports that can help.

A number of organizations, both national and local, can help you find the information and services that are right for you.

- Call **2-1-1** to reach a nationwide resource and helpline supported by the United Way.
- **Area Agencies on Aging** are federally funded programs open to all people aged 60 and older. Many are linked to a network of support services and can provide some services and refer you to others.
- The **National Institute on Aging-Alzheimer's Disease Education and Referral (ADEAR) Center** is an online service that offers a lot of practical information.
- The Family Caregiver Alliance, founded in the 1970s, was the first community-based nonprofit organization in the country to help caregivers. It operates the **Family Care Navigator**, which can help you identify resources in your state.

Slide 12:

A number of other online resources are available to help caregivers locate resources.

- The **National Respite Locator Service** can help you find respite in your local area.
- The U.S. Administration on Aging operates the **Eldercare Locator** which connects caregivers and older adults to services in their state and local area.
- You can also visit the website of the **National Adult Day Services Association** to find an adult day service program located near you and/or the person living with dementia.
- Veterans may be eligible for assistance through the **U.S. Department of Veterans Affairs**. The websites provided will help you identify possible programs and services for veterans who are living with dementia.

Slide 13:

When seeking services from community-based organizations such as the Alzheimer's Association or an Area Agency on Aging, you may be asked questions about your personal needs and wishes. Professionals in these organizations can help you develop a care plan, along with important resources and information, about how and where you, as a caregiver, can identify appropriate services and programs that are most likely to be of benefit; and/or begin to practice self-care as discussed earlier.

Care to Plan, a free online service, works with caregivers to find help that fits the current needs of the caregiver and the person living with dementia. This tool takes 5-10 minutes to complete and creates for you an individualized support plan, including information about support services in your local area. You can print out or save the plan to use when talking with home care and community-based service professionals to find the services that are best for you.

Your care plan should be reviewed periodically.

Slide 14:

In conclusion:

- Take steps to maintain your own health. It is the key to giving better care to the person living with dementia, and can improve your caregiving experience.
- Taking care of your health allows you to remain active and effective as a caregiver.
- Treat existing health problems and pay attention to other problems as they happen, especially stress.
- Use regular respite or other services that allow you to refresh yourself and regain your strength, health, and positive outlook.