



For the Lifespan: The Caregiver Guide

Module 5

Taking Care of the Caregiver

Leader Guide

Module 5

Taking Care of the Caregiver

PURPOSE

The job of a caregiver can be time-consuming and complex, but can also be very rewarding. The purpose of this module is to instruct caregivers on how to make their tasks easier, more organized, and more effective while taking care of themselves throughout the process.

OBJECTIVES

After completing this module, participants will be able to:

- Understand your rights as a caregiver.
- Understand the importance of making time for you.
- Learn how to combat “compassion fatigue”.
- Identify some ways to better care for their health.
- Learn tips on juggling working and caregiving.

The Participant Guide includes:

- Local community resources
- State resources
- Website and national resources

SLIDE 1

UCare
For the Lifespan: The Caregiver Guide
Module 5
Taking Care of the Caregiver

INTRODUCE

Introduce yourself and allow everyone present to introduce themselves and explain their caregiving role.

NOTE

This is an excellent time to set the tone of the training. Be friendly, relaxed, and focused. Remember names or use name tags.

ASK

What would you like to get out of the training today?

NOTE

Put responses on a white board and during the training refer back to them. Put a check by specific topics discussed.

TELL

The handouts are yours to take home. There is room to write on the handouts during the training session.

SLIDE 2

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SLIDE 3

Family Stories

Teresa was responsible for caring for her 88-year-old father. Between keeping track of her father's prescriptions, his bowel and bladder issues, and visits to the doctor, Teresa could barely keep up with her parenting responsibilities, much less her obligations at work. The stress she experienced contributed to health problems and marital strain. Teresa's stress was high and she was feeling very discouraged. She talked to her friends about her problems, but was afraid they would get sick of her complaints. Teresa knew she needed help, but felt guilty. She thought, "I should be able to *deal* with this!"

NOTE

Share this story.

Tell participants this is only one example of a caregiving situation and their own situation might be different.

TELL

Invite participants to share their own stories.

Remind them to remember to respect the confidentiality of the group members. What is shared among the group should not leave the room.

Remind participants that it is OK to have mixed feelings about being a caregiver.

SLIDE 4

Family Feelings

- Having positive and negative feelings about caregiving is common.

- Negative feelings may include worry, irritability, sadness, anger, and stress.
- Caregivers who also parent are called the “sandwich generation”.
- It is common to want support.
- It is just as common to deny one’s need for support out of feelings of guilt or lack of information about resources.

ASK

What kinds of feelings do you have about caregiving? Negative? Positive? Have you thought about reaching out for support? If it is difficult to reach out, let’s brainstorm about making reaching out easier.

Next we are going to discuss a Caregiver Bill of Rights. What rights do you have as a caregiver?

SLIDE 5

Caregiver Bill Of Rights:

As a caregiver, I have the right:

- To take care of myself. This is not being selfish, but a tool to take better care of the person I care for.
- To seek help from others even though the person I am caring for might object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own personal life. I know that I do everything that I reasonably can for this person, and I have the right to do things for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.

SLIDE 6

Caregiver Bill of Rights: (cont.)

- To reject attempts by the person I care for to manipulate me through guilt and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from the person I care for, as long as I offer these qualities in return.
- To take pride in what I am accomplishing and applaud the courage it has taken to meet the needs of the person I am caring for.

SLIDE 7

Caregiver Bill of Rights: (cont.)

- To protect my individuality and my right to make a life for myself that will sustain me in the time when help is no longer needed by the person I am caring for.
- To expect and demand that as new strides are made in finding resources to aid persons with physical and cognitive disabilities in our country, similar strides will be made towards aiding and supporting caregivers.

Adapted from Caregiving: Helping an Aged Loved One, by Jo Horne, 1985, Salt Lake County Aging Services – A Caregiver's Guide.

ASK

Which of these rights is the most challenging for you? Why?

TELL

Suggest to participants that they keep a copy of this Bill of Rights handy to review regularly, especially when they are having hard days.

TELL

Caring for someone often requires close attention to basic hygiene and safety considerations.

ASK

What are some basic safety and hygiene issues in caring for someone that will protect yourself and the person you care for?

SLIDE 8

Safety and Hygiene

- Treat all blood and bodily fluids as if they might be contagious and contain blood borne pathogens.
- Use gloves, face masks, and other protective equipment when needed to protect yourself and others.
- Protective equipment should be used whenever contact with bodily fluids may occur.

TELL

Use gloves, face masks, and other equipment to protect yourself whenever contact with bodily fluids may occur.

Making/taking time for yourself is often challenging and you may feel that you are inadequate if you can't do it all!

SLIDE 9

Use Help and Resources

- Accept that you cannot do everything on your own. Use help from family and friends and the resources available to you.
- Accept a variety of feelings in yourself as you care for another person.

- Accept that you also have needs that need to be met if you are to continue as a caregiver.
- Use respite care services to help relieve some of the stress felt by providing full time care for another person.

ASK/TELL

Why is it important to use help from family and friends and other resources? You may experience a variety of feelings and you do have needs that should not be neglected. You cannot and should not do everything on your own. What help, support, and respite services are available to help you?

What is compassion fatigue?

SLIDE 10

Addressing Compassion Fatigue

- Attend groups for caregivers who are interested in learning pertinent skills. Check with your local Agency on Aging or www.caregiver.com.
- Talk with family members and friends about feelings.
- Talk with clergy members or spiritual advisors.
- Blog or write about your experiences as a caregiver.

TELL/ASK

Caregiver groups can provide an outlet to express your feelings and struggles experienced while caring for someone. Check with your Area Agency on Aging or www.caregiver.com to find support groups. What are the pros and cons that you have experienced with caregiver groups? Are there other groups available that you have found useful? Other individuals? Talking with friends, family, or clergy; and writing can be good outlets.

SLIDE 11

Protecting Your Privacy and Possessions

- Maintain privacy when using outside help.
- Consolidate important documents.
 - Helps when planning appointments.
 - Allows for easier securing of information.
 - Less likely to be misplaced or disposed of.
 - Less likely to be seen by others.
- Lock up money, checks, credit cards, jewelry, and valuables.
- Avoid letting providers use auto, phone, or home for personal use.

TELL

It is important to maintain the privacy of the care recipient when you have outside help. Keep critical, confidential information in a central secure location. Lock up your valuables. Avoid letting providers use your home, car, or phone. Does anyone have other suggestions or comments?

SLIDE 12

Attending to Your Physical Health

- Eat healthy meals.
- Get adequate sleep.
- Maintain your regular medical checkup schedule.
- Participate in a regular exercise program.
- Manage and reduce stress levels.

ASK

Why is it important to attend to your physical health, including thinking about nutrition, sleep, exercise, and stress

management? What are some areas you might work on improving?

SLIDE 13

Strategies

- Daily relaxation.
- Engaging in spiritual activities/practices you find renewing.
- Talking with trusted friends (and others) about your real feelings as a caregiver.
- Participating in a hobby or activity you find enjoyable.
- Giving yourself regular caregiving breaks.
- Socializing with others.
- Regularly using respite care services available to you.

ASK

This slide lists different useful strategies that help attend to your psychological health. Which do you think are the most helpful? Are there any other strategies that you have used or seen others use successfully to deal with stress?

How comfortable are you in using a team approach to caregiving? In delegating to others?

SLIDE 14

Team Approach

- Try to use a “team” approach to caregiving.
- Be assertive when communicating.
- Delegate responsibilities to others.
- Take turns with difficult tasks.
- Encourage one another.

DISCUSS

There are a number of barriers to teaming and delegating. One of the most common is communication. You know what you want to communicate, but it is difficult to say what you need directly and clearly. When you are talking with others, the more pleasantly assertive you can be in your communication, the more likely you are to achieve positive outcomes. Assertive communication includes both listening to where others are coming from and then sharing your own perspectives about what is needed. If you can't find common ground, invite a neutral third party (social worker, minister, etc.) to move the communication forward.

ASK

What ideas do you have about communicating clearly and effectively?

SLIDE 15

Communicating

- Active listening:
<http://www.mindtools.com/CommSkill/ActiveListening.html>
- Assertive communication tips:
http://www.twu.edu/downloads/counseling/e-1_assertive_communication.pdf
- Creating support communities:
www.lotsahelpinghands.org
- Geriatric case managers:
<http://www.caremanager.org>

TELL/ASK

These websites have more information on communication, listening, creating support communities, and case managers. Are you aware of other helpful websites?

What are some challenges in encouraging someone to do a task themselves rather than relying on someone else to do it for them?

SLIDE 16

Fostering Independence in Family Members

- Be patient – the dependent person in your care may take longer to accomplish a task than you.
- Trust someone’s capacity to problem-solve.
- Speak in adult, non-patronizing tones.
- Be encouraging and praise successes.
- Have expectations.
- Remember, if they can do it, they should do it!

TELL

Although you are providing caregiving, the care recipient needs to be as independent as possible. Be patient, trust their abilities to problem-solve, speak to them as an adult, and be encouraging. Praise successful efforts, even small ones! Have expectations - if they can do it, let them do it. The more you can empower the person you care for, the better!

SLIDE 17

Organizing Medications

- Make a list of all their medications and place in a folder with dosage amounts and times.

- Include contact information for doctors and other medical professionals providing care, as well as the pharmacy that fills prescriptions.
- Bring the folder with you to all medical visits / appointments and keep handy for all related phone conversations.

TELL

Structure and predictability are important for both you and the care recipient. Organization can include things from daily routine management, medication management, socialization activities, tracking important information, delegation of tasks, and more. It is helpful to begin with a list of what needs to be done and then sort this list into categories, such as where things need to take place (appointments, for example), or who needs to accomplish the various tasks. One size does NOT fit all!

This is one way to organize medications. Make a list of medications, including dosage, contact information, and the pharmacy. Keep this information in a folder that you take with you to medical appointments.

SLIDE 18

Caregiving Responsibilities

- Make a list of every person and every agency available to help with caregiving responsibilities.
- Make a list of everything the care recipient needs help with on a daily, weekly, or monthly basis.
- Include even the most seemingly trivial things such as washing laundry, socialization opportunities, or exercise routines.

SLIDE 19

Caregiving Responsibilities (cont.)

- Cross examine each list determining:
 - Who can help with what.
 - What can be done with minimal support.
 - What you need to personally take care of, etc.
- Enlist the help of your support system and available resources to accomplish the execution of the list.
- Review the list(s) periodically to assess changing needs and resource availability.

TELL/ASK

Make lists of what is needed on a daily, weekly, and monthly basis. List every person and agency that can help with different tasks. Ask for help from your support system and any available resources. Review and update your lists every few months.

How many of you are juggling caregiving and careers? Do you have any tips or ideas that help you manage?

SLIDE 20

Some Useful Juggling Tips

- Speak up! Talk to your boss before exhaustion affects your work. Minimize details, and emphasize that you are doing your best.
- Negotiate a flex schedule – if possible, try to negotiate a schedule that better fits your caretaking tasks.
- Negotiate a telecommuting position – if possible, depending on the type of work you do.
- Investigate! See if your company has any kind of programs or resources available for you.

- Divide and conquer! Have a network of helpers and support persons to assist you with caregiving.

TELL

Speak up and talk to your boss. Be pleasantly assertive. It never hurts to ask if a more flexible schedule or telecommuting is a possibility. Develop a network of helpers and support people to help you with caregiving. In most communities there are a variety of resources available to assist in caregiving. Using these resources can help ease some of the stress you may feel as a caregiver. Examples of community resources can include: home health care services, non-medical home care services, adult day care, respite care, meal delivery, and transportation services. Look at reviews and evaluations when choosing respite providers. There are websites with more information listed at the end of your Participant Guide.

SLIDE 21

Reinventing Your Attitude

- When faced with overwhelming demands, it is often necessary to reinvent our attitude.
- What discoveries are you making?
- How are you growing in your ability to love?
- Focus on the present.
- Look for moments of pleasure and enjoyment and string them together.
- Caregiving may be burdensome, but it can also be a gift.

TELL

When faced with overwhelming demands that we cannot alleviate, it is often necessary to reinvent our attitude.

Look for the meaning in your role as caregiver. Focus on

the present. Seek out moments of pleasure or enjoyment. Try to think about the positive aspects and how caregiving is a gift.

ASK

What discoveries are you making about yourself and your abilities to withstand stress and strain? How are you growing in your ability to love not only others but yourself? What are some of the gifts of caregiving?

SLIDE 22

Four Kinds of People

Former First Lady Rosalynn Carter once said, "There are four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers."

SLIDE 23

Take a Break

- Ask for help!
- Develop a master list of what you need to do.
- Highlight the tasks you don't like to do or are difficult.
- Use this list to make a Help List.
- Share the list with family and friends.
- Ask them for help.
- Review this list often and update.
- Recognize that you need help!
- Acknowledge that you can't do it all!

SLIDE 24

Things to Remember

- Remember to take good care of yourself by staying positive, exercising regularly, getting enough rest, eating nutritiously, using good body mechanics, keeping a sense of humor, relaxing, and doing something enjoyable when you can.
- Always believe in yourself and your abilities.
- Remember that you have the strength, courage, compassion, and wisdom to succeed.
- Thanks for your participation.

TELL/ASK

Don't forget to take good care of yourself! How do you do that? (Mention the points above if not mentioned by participants).

Although caregiving can be a burden, it can also be a gift. Always believe in yourself and your abilities. Remember that you have the strength, courage, compassion, and wisdom to succeed. Thanks for your participation. You've been a great audience! I would be happy to discuss any of these topics further with you after class. I wish you the best in your caregiving efforts!

ADDITIONAL RESOURCES

AARP	www.aarp.org
Administration on Aging	www.aoa.gov
American Red Cross	www.redcross.org
Eldercare Locator	www.eldercare.gov
Utah Health Insurance Marketplace	http://www.avenueh.com

Utah Healthcare by area, program, I & R

www.health.utah.gov/disparities/healthcareinutah.html

Medicare www.medicare.gov

Medicaid www.medicaid.gov

National Assoc of Area Agencies on Aging www.n4a.org

National Family Caregivers Association www.nfcacares.org

National Respite Locator Service www.respitelocator.org

Nursing Home and Health Care Quality Initiative
www.medicare.gov/NHCompare/home.asp

Utah Coalition for Caregiver Support www.hsdaas.utah.gov
www.caregivers.utah.gov

UCARE MODULE TOPICS

1. Providing Personal Care
2. Dementia and Memory Loss
3. A) Caring for Older Adults with Chronic Health Issues
3. B) Caring for Children with Special Health Care Needs
4. The Accessible Home
5. Taking Care of the Caregiver
6. Caring for those with Depression, Anxiety, Stress, or Mental Health Issues
7. Community Supports for Remaining at Home
8. Working Effectively with In-Home Service Providers
9. Keeping Your Home and the Person You Care for Safe
10. Eating Healthy for Life
11. Assistive Devices: Tools to Help You
12. Legal and Financial Matters: What You Need to Know

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For more information, please visit: <http://www.ucare.utah.gov>,
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