



For the Lifespan: The Caregiver Guide

Module 5

Taking Care of the Caregiver

Participant Guide

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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.

WHAT YOU WILL LEARN

After completing this module, you 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 your health.
- Learn tips on juggling working and caregiving.

This Participant Guide includes:

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

FAMILY STORIES

Teresa was responsible for caring for her 88-year-old father in addition to her two young children. Between keeping track of her father’s prescriptions, his bowel and bladder problems, 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 of her own and caused tremendous strain on her marriage. Teresa was not sure she would be able to continue for much longer with all of these responsibilities. She wanted to talk with her friends about her struggles, but worried that they would become annoyed over time if this is all she spoke about. Teresa wanted to reach out for additional support, but sometimes felt guilty that she simply couldn't just "deal with it" on her own.

FAMILY FEELINGS



Teresa's positive and negative feelings and experiences are common among caregivers whose time is divided between competing demands. Teresa is part of what is known as the "sandwich generation" or the generation of caregivers who are caring for aging parents at the same time they are raising children of their own. These types of multiple responsibilities can lead to feeling overwhelmed, anxious, and depressed. As with many caregivers, although Teresa realizes she needs extra support, she is unsure how to find it, and she has placed such high expectations on herself that she is not sure she deserves it.

Teresa's situation is just one example of a caregiving situation. Not all caregivers provide support for aging parents. A caregiver may be assisting a non-family member in their community as well as another family member who is disabled or terminally ill.

In the following sections, we will provide information about how to care for yourself in the context of voluntarily caring for someone with mental health, medical health, aging, and/or disability related issues.

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.
- To reject attempts by the person I care for (either consciously or unconsciously) 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.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my 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.

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

SAFETY AND HYGIENE



In order to keep yourself, your family, and the person you care for safe, it is advised that you practice the following safety standards.

- 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.

More information about safety is in Module 9, Keeping Your Home and the Person You Care for Safe.

USE HELP AND RESOURCES



As a caregiver, you cannot do everything on your own. If you try, you will likely only increase your feelings of inadequacy, frustration, anger, and resentment. While some levels of these feelings are present for all caregivers, how you choose to attend to your own needs can lessen the degree you experience these feelings. There are several tips you can use to help in your quest to make time for yourself, and provide yourself with a needed break.

1. Accept that you cannot do everything on your own. Use the help and resources available to you from the community you live in, and your family and friends to provide yourself with a break from your caregiving responsibilities.
2. Accept a variety of feelings in yourself as you care for another person. These feelings do not mean that you are

lacking or inadequate in your abilities to care for them, only that you are human. Caring for another person full time is a stressful, time-consuming job.

3. Accept that you also have needs that need to be met if you are to continue as a caregiver. Being a caregiver is a full time job, one that is often assumed unexpectedly in addition to other responsibilities such as raising your own children. Despite this, it is important that you take time to participate in activities you find enjoyable, such as reading a book just for fun, watching a television program, roller skating, craft projects, spending time with friends, and other activities.
4. Use respite care services to help relieve some of the stress felt by providing full time care for another person. There are several options available in many communities to do this and may include options such as Adult Day Care, community center activities, non-medical home care agencies, companionship volunteers, and other local resources.



COMPASSION FATIGUE



Compassion fatigue is the tired, worn-out feeling experienced by caregivers who do not take time for themselves apart from their caregiving responsibilities. Compassion fatigue is common among individuals who choose to care or provide services for others, but there are several things that can be done to combat this. Caregivers include both men and women of all ages. Select a group (or groups) that will best meet your individual's needs.

Some options are:

- Attending groups for caregivers who are interested in learning pertinent skills.

- Talking with family members and friends about feelings.
- Talking with clergy members or spiritual advisors.
- Blogging or writing about your experiences as a caregiver.

Caregiver groups can provide an outlet to express your feelings and struggles experienced while caring for someone. Many groups offer trainings and education about topics pertaining to caregiving. Each group can have a different goal and/or take a different form. Some groups are organized around caring for people with a specific illness or disease and others are a place to share ideas with others. Some groups take place via the internet and others in person. Information about local support groups is available through local Area Agencies on Aging, health-specific organizations, health professionals, and social workers. You can also find support groups listed under local resources on www.caregiver.com for Cache, Weber, Davis, Salt Lake, and Weber Counties. Rural caregivers are advised to call the State Office of Rural Health at 801-538-6113. When choosing a support group or support groups to attend, it is important to find one that meets your needs and convenes at times that you will be regularly available to attend.



Family members and friends can be a great source of strength and support for you in your caregiving efforts. They provide a source of socialization, and reduce the isolation often felt by caregivers. Talking with these individuals can also help to validate your feelings of frustration, anger, and irritation. Talking with other family members and friends can also provide you with an opportunity to organize respite care and help provide for the needs of the person you are caring for.

If you are connected to a spiritual or religious tradition, speaking with laypersons or clergy can provide you with much needed emotional and spiritual support. Part of the job of a clergy member is to be available to provide restoration and prayer for a congregant in need, so do not hesitate to reach out.

PROTECTING YOUR PRIVACY AND POSSESSIONS

It is important to maintain the privacy of the care recipient as much as possible as well as your own when using outside help. Important documents should be consolidated to a central location. This will help when planning appointments and will allow for easier securing of the information contained in the documents. This will also make it less likely for the documents to be unintentionally misplaced or disposed of as well as reduce the chances of document review by individuals with no need to see such documents.



You should also minimize the chance of theft. Lock up your money, your checks, credit cards, jewelry, and other valuables. Avoid letting service providers use your car, phone, or home for personal use.

CARING FOR YOUR HEALTH

Attending to Your Physical Health



Many caregivers feel as if they do not have time to focus on their own health. Caring for your own needs, however, can help you to have strength and energy to care for the person you care for.

Some key physical self-care activities include:

- Eat healthy meals.
- Get adequate sleep.
- Maintain your regular medical checkup schedule.
- Participate in a regular exercise program.

- Manage and reduce stress levels.



Attending to Your Psychological Health

Many caregivers also feel as if their thoughts, feelings, and desires are no longer important in comparison to the needs of the person they are providing care for. Staying aware of your own psychological needs and reserving time/energy to participate in non-caregiving activities that you enjoy will improve the quality of the care you can provide. Some activities you may find helpful include:

- Daily relaxation.
- Engaging in spiritual activities/practices you find renewing and helpful.
- 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.



It is important to remember that you are not a superhero, and no one is expecting you to be (except, perhaps, you!). You have to be able to realistically appraise how you are doing and feeling as a caregiver, and seek help and support when needed. Be aware of what you can do and how much you can provide, but do not be afraid to face your limitations. You are only human. Part of the learning involved in being a caregiver is learning that we all have limits, and that having limits is OK.

People in caregiving roles often experience an array of emotions from despair to joy and back. Experiencing a range of feelings is not only normal, but healthy as well. If you find yourself “stuck” in negative emotional states (such as anxiety and depression)

that persist for several weeks, and these moods interfere with your ability to function, then you will likely benefit by reaching out to a local mental health agency who can provide you with guidance and support. It is very common and often quite helpful for caregivers to seek out support outside of their own family and friends. Family members may be struggling with similar issues and might not be able to be as supportive as an objective party can be.

DELEGATE, DELEGATE, DELEGATE



The most successful caregivers are the ones who use a “team” approach to caregiving. This means it is OK to delegate responsibility to others, take turns with arduous tasks, and encourage one another through the tough times. 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. Part of assertive communication is learning to listen to others with an open mind and seeking first to understand where someone is coming from, then giving your own opinions. If you find that you and others are struggling with sharing responsibilities, consider bringing in a neutral professional (social worker, LPC, chaplain, care manager, or professional mediator, etc.) to act as an objective third party. For additional information, visit the following webpages:

Active listening:

<http://www.mindtools.com/CommSkll/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>

FOSTERING INDEPENDENCE IN DEPENDENT FAMILY MEMBERS



The more you can foster independence and empower a care recipient, the better! To “empower” means you help your care recipients find the tools, skills, and sometimes self-confidence to help themselves, rather than doing something “for” them.

People who are able to help themselves generally have higher levels of self-esteem and efficacy. Here are some strategies for fostering independence in dependent family members:

- Be patient – the dependent person in your care may take longer to accomplish a task than you would take. Try to be patient and accept that things may take longer than you would like. Otherwise, you will find yourself doing everything!
- Trust someone’s capacity to problem-solve – you may find the person who depends on you struggling with a simple task like opening a candy wrapper or deciding whether to throw something in the garbage or the recycle bin. Although they may not accomplish the task in the way you would, these tasks may be within their reach.
- Speak in adult, non-patronizing tones – although you may feel very frustrated at times, remember to treat the care recipient with respect and have expectations that match their capacity. If you treat an adult like a child, he or she will become less and less capable, an unfortunate self-fulfilling prophecy.

- Be encouraging and praise successes – no matter how small the success, notice their efforts and praise their successes.
- Have expectations – regardless of someone’s current level of incapacity, they are usually able to take care of some of their basic needs and may even be able to contribute to a household routine. Don’t let guilt get in the way of having reasonable expectations of the person you are caring for.
- Remember, if they can do it, they should do it!

ORGANIZING FOR SUCCESS

Organization helps to provide structure and predictability to both you and the person you are caring for. 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. No one organizational method will work best for everyone, so you may need to try a few out and see what fits your needs best. Some examples are provided below.



Organizing Medications

- Make a list of all their medications and place in a folder with dosage amounts and times as applicable.
- Include contact information for doctors and other medical professionals providing care, as well as the pharmacy used to fill prescriptions.
- Bring the folder with you to all medical visits/appointments and keep handy for all related phone conversations.

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.
- 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.

JUGGLING CAREGIVING AND CAREER



Here are some tips for trying to manage the multitude of responsibilities that can come from trying to juggle a part- or full-time career with being a caregiver.

- Speak up! The first thing you need to do is talk with your boss before physical and mental exhaustion affects your work. Minimize the details, and maximize that you are doing your best, but be realistic about the toll some of the caregiving responsibilities might have on your work.
- Negotiate a flex schedule – if possible, try to negotiate a more flexible schedule that better fits your caretaking responsibilities. Perhaps you can go into work later, but stay later when another caregiver can be with the person you care for.

- Negotiate a telecommuting position – depending on the type of work you do, you might be surprised how willing many managers are to consider letting you work from home some days. There is no harm in asking for what will work, even if you do not get it.
- Investigate! More and more companies are realizing how many of their employees carry the extra burden of caregiving responsibilities. See if your company has any kind of programs or resources available for you.
- Divide and conquer! The only real way to manage a career and caregiving is to have a network of helpers and support persons who will assist you in your caregiving responsibilities.

RELYING ON COMMUNITY SYSTEMS AND RESOURCES



In most communities there are a variety of resources available to assist in caregiving. Utilizing 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.

When considering respite care, it is important to look at reviews and evaluations available for the agency or facility. Choose the options that best fit the needs of both you and the person you are caring for. See the resources below for information about how to contact and access an array of support services. Module 7, *Community Supports for Remaining at Home*, has more detailed information on these resources.

FINDING MEANING: LIVING WITH DIGNITY AND PRIDE



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. 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? Focus on the present, rather than dwelling on disappointments of the past or anxieties about the future. Look for moments of pleasure and enjoyment and string them together to weave pleasant memories in the midst of hardship.



Caregiving, while it can be burdensome, can also be a gift. You are in the unique position of aiding another human being who is vulnerable and requires ongoing assistance. Being the person someone else depends on can imbue your life with a deep sense of purpose or fulfillment. And remember, sometime down the road, there is likely someone who will be that person for you.

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."

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

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

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Marilyn Hammond, Ph.D., Utah State University

Judith M. Holt, Ph.D., Utah State University

Jeanie Peck, LCSW, Utah State University

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Sonnie Yudell, Program Manager, Utah Caregiver Support Program,
Utah Division of Aging and Adult Services

Utah Coalition for Caregiver Support Project Management Team

Lynn Long

Maurice Wells

Clara McClane

Margene Luke

Nick Zullo

Terresa Newport

Simone Black

Elizabeth Squires

Laura Owen Keirstead

Rhonda Hypio

Megan Forbush

Kathy Nelson

Carrie Schonlaw

Paula Ledford

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Connie B. Panter, Utah State University

Lynelle Chenn, Utah State University

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

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