



Healthy Caregiving

September 2019

Emily Roberts, Ph.D.
Assistant Professor

Kristopher M. Struckmeyer, Ph.D.
Assistant State Specialist for Caregiving

Whitney A. Bailey, Ph.D.
Associate Professor

Luis Mejia P., M.A.
Doctoral Student

Sarah Gordon, PhD.
Associate Professor

Oklahoma Cooperative Extension Fact Sheets
are also available on our website at:
facts.okstate.edu

The Caregiving Experience

Caregivers experience different journeys, some care for a care recipient with a short acute illness or surgery. Some caregivers give lifelong care to one person over decades or take on several care roles intermittently. This means that a caregiver may have various roles in hands-on tasks like bathing or toileting or other support through cooking, cleaning and paying bills.

The way the family (as a whole) and each member views the role of the caregiver can be complex. It may be because that person took care of me, now it is my turn. Others may feel that it is their duty because they love the person who needs help. They may take on the caregiving role whether they are ready for the responsibility or not.

With little information or training on how to provide care, there are risks in being a caregiver. Often there are strains in family relationships because of poor communication, this may lead to stress and illness for the caregiver. Feeling stressed or anxious all day, every day is exhausting. It is not good for your body, heart or mind. The following tips will help you understand the caregiving role and the role of the people around you in the caregiving journey.

Identifying the Care Team

Many friends and family around you do not know what kind of help is needed. Think about who you can call on when an extra hand is needed. Use their strengths to help you and assign tasks to them that you feel comfortable allowing them to do like running errands, house cleaning, grocery shopping, etc.



Roles and Responsibilities

Every once in a while, step back and assess the situation. What is being done? What is not being completed? Manage your care team accordingly. Don't be afraid to check in!

Stages of Care

(See Caregiving 101 Factsheet for further explanation)

- Pre-care
- Care Activation
- Crisis Care
- Sustained Care
- Care Transitions

There are many steps that you can take to protect yourself from the health risks of caregiving throughout the caregiving journey. These steps will help you see the warning signs when extra help is needed and will allow you to remain resilient (strong mentally and physically) in the caregiving role through all of the stages of care.

Pre-care Action Steps

In the pre-care stage, caregivers have not begun to provide care yet. The healthy way for families to provide care in this stage is to discuss the care plan. It is important for you and

your family to identify risks in caregiving so you know who can do what. Do not forget to ask the care recipient's opinion on what they may want!

A good strategy is to write down everyone's wishes, expectations and resources the care team has access to. This will help in later stages.

Tips:

- Be able to name all of the duties of your caregiving role
- Identify the risks to your health
- Assess the meaning of care, what does it mean to you and your family?
- Find ways to adapt (what has worked well in the past?)
- Create a care plan and identify who can do what
- Ensure the care recipient's opinions and suggestions are considered
- Document wishes, expectations and resources

Care Activation

In this step, you begin to activate your care plan. One of the most important things in this stage is to know when care has been activated. This may seem silly but caregiving can sneak up on people. It is important to know when care needs warrant the care plan being activated. A common pitfall is when individuals avoid taking the planned action mapped out in the pre-care phase.

As you begin to provide care, needs will change, so find out how the family's goals may have changed. Continually check in to identify current and new resources.

Tips:

- Modify the care plan as needs and expectations change
- Identify family goals as needs change
- Identify and access resources

One of the most important reminders is that family members often have the one common goal (ex. keeping a person safe, in the home, near family, etc.) for the care recipient. It is a great tool to remind one another about this common goal. One strategy to keep families anchored is to focus on the "musts" of the care plan. Sometimes other things come up that seem urgent but aren't as important as the larger caregiving goal.

Tips:

- Identify the most important priority and structure other priorities around it.
- Limit to three things that must be done that day. This keeps you from feeling overwhelmed
- Think before you commit. Make sure you have the resources and time to complete the activities. If not, delegate to someone else

Crisis Care

Crisis care is a very stressful time for families. This can be at the time of a fall or life-threatening illness or at a time when the care recipient is not feeling in control. During this time, it is important that families keep communication open between members, stick to the care plan and only adapt that plan if necessary.

A good strategy is to always use family goals to anchor conversations back to what is important. Do not forget to promote the care recipient's autonomy. If there are changes, be sure to ask the individual about what they'd like.



Tips:

- Communicate openly among family members
- Stick with the care plan and adapt only if necessary
- Keep family goals clear to all members
- Promote the care recipient's autonomy and discuss changes with the individual

Sustained Care

As families move to sustained care, routines begin to set in. Be sure to continually check to see what new resources have appeared and begin to assess resources when needed. Remember—only to assist individuals on tasks when assistance is needed. Help promote a level of independence by ensuring their abilities are not undermined (remember that you like to be independent). Stick to the care plan and support yourself with the care team. Remember that you don't have to do everything yourself. Finally, make sure to continue to identify family goals as needs change.

Tips:

- Identify resources and assess long-term opportunities (ex. home health aid)
- Maintain the independence of the individual
- Continued implementation of care plan
- Utilize care team frequently
- Identify family goals as needs change

Care Transitions

There will be numerous transitions along the care journey. Care transitions can mean a major change in care (move from home to facility) OR an end to care, as with death. In this stage, it is very important to identify and access resources that can help you along the way (ex. Lawyer, long-term care facility, etc.). Care transition options should be discussed early in the caregiving journey with family members.

Tips:

- Identify resources for transitions
- Develop a plan for such transitions

Taking Care of Yourself

As the primary caregiver for your loved one, it is important you take care of yourself! If you aren't feeling well, there is an increased risk of hurting both you and the care recipient. It's not healthy for you to feel exhausted and stressed all day, high stress levels can weaken your immune system, cause emotional problems and even cardiovascular problems. It is important to you take time for yourself. Get away from your loved one and take some time to de-stress. Read a book, go for a walk or see a movie to promote better physical and emotional health.

Always remember:

- Be honest with yourself about what you really need to de-stress.
- When you're feeling ill, go see a doctor. If you begin to feel ill, you cannot provide the best care.
- As a caregiver, you're a busy person. It is okay if you need to quit things. You need to take care of you!
- Take care of your relationships. Depend on support from your care team so you can go socialize. Everyone is entitled to a break, so do not feel guilty if you need some time to yourself.

- For more information about the many aspects of the caregiving role, please look to other fact sheets in our Caregiving Series.

References

- Bailey, W. A., & Gordon, S. R. (2016). Family caregiving amidst age-associated cognitive changes: Implications for practice and future generations. *Family Relations*, 65, 225-238. doi:10.1111/fare.12176
- Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education*, 46, 357-367. doi:10.1080/19325037.2015.1099482
- National Alliance for Caregiving, & AARP Public Policy Institute. (2015). Caregiving in the U.S. 2015. Retrieved from <http://www.caregiving.org/caregiving2015>
- Roberts, E., & Struckmeyer, K. (2018). The impact of respite programming on caregiver resilience: Perspectives of primary family caregivers of individuals with dementia. *Inquiry-The Journal of Health Care Organization Provision and Financing*. 55,1-11.

The Oklahoma Cooperative Extension Service

WE ARE OKLAHOMA

The Cooperative Extension Service is the largest, most successful informal educational organization in the world. It is a nationwide system funded and guided by a partnership of federal, state, and local governments that delivers information to help people help themselves through the land-grant university system.

Extension carries out programs in the broad categories of agriculture, natural resources and environment; family and consumer sciences; 4-H and other youth; and community resource development. Extension staff members live and work among the people they serve to help stimulate and educate Americans to plan ahead and cope with their problems.

Some characteristics of the Cooperative Extension system are:

- The federal, state, and local governments cooperatively share in its financial support and program direction.
- It is administered by the land-grant university as designated by the state legislature through an Extension director.
- Extension programs are nonpolitical, objective, and research-based information.
- It provides practical, problem-oriented education for people of all ages. It is designated to take the knowledge of the university to those persons who do not or cannot participate in the formal classroom instruction of the university.
- It utilizes research from university, government, and other sources to help people make their own decisions.
- More than a million volunteers help multiply the impact of the Extension professional staff.
- It dispenses no funds to the public.
- It is not a regulatory agency, but it does inform people of regulations and of their options in meeting them.
- Local programs are developed and carried out in full recognition of national problems and goals.
- The Extension staff educates people through personal contacts, meetings, demonstrations, and the mass media.
- Extension has the built-in flexibility to adjust its programs and subject matter to meet new needs. Activities shift from year to year as citizen groups and Extension workers close to the problems advise changes.

Oklahoma State University, as an equal opportunity employer, complies with all applicable federal and state laws regarding non-discrimination and affirmative action. Oklahoma State University is committed to a policy of equal opportunity for all individuals and does not discriminate based on race, religion, age, sex, color, national origin, marital status, sexual orientation, gender identity/expression, disability, or veteran status with regard to employment, educational programs and activities, and/or admissions. For more information, visit <https://eeo.okstate.edu>.

Issued in furtherance of Cooperative Extension work, acts of May 8 and June 30, 1914, in cooperation with the U.S. Department of Agriculture, Director of Oklahoma Cooperative Extension Service, Oklahoma State University, Stillwater, Oklahoma. This publication is printed and issued by Oklahoma State University as authorized by the Vice President for Agricultural Programs and has been prepared and distributed at a cost of 20 cents per copy. 0919 GH.