AgeSense adapting to life's changes

Fact Sheet

AgeSense: The Caregiving Journey

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Introduction

While you might expect to be in a caregiving role as you reach middle age, one southwest Kansas participant in a "Powerful Tools for Caregiving" class found herself in the sandwich generation at age 42. Lynette had two teenage children and a husband who had experienced a traumatic brain injury as the result of an accident. Then, following her mother's death, she found herself caring for her father, who suffers from chronic obstructive pulmonary disease (COPD). While her job as a registered nurse gave her many caregiving skills, Lynette found herself feeling stressed as she tried to meet everyone's needs. She felt like she was coming apart at the seams. What did she need to do first?

Significance of Caregiving Issues

Current newspaper or magazine articles, as well as research, illustrate the increasing significance of caregiving issues, the cost to the country, and the effects on the lives of many families. For example, former first lady Rosalynn Carter has made this issue one of her life projects through the Rosalynn Carter Institute for Caregiving at Georgia's Southwestern State University, her alma mater in Americus, Georgia. (*www.rosalynncarter.org*)

Carter has said there are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers. According to a study by the National Alliance for Caregiving and AARP, about 30 percent of the U.S. adult population — 65.7 million people — provide care to someone who is ill, disabled, or aged. Statistics from the Alzheimer's Association indicate that 43.5 million of adult family caregivers care for someone 50 years of age or older and 14.9 million care for someone who has Alzheimer's disease or other dementia.

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While caregivers are found across the age span, the average age of a caregiver is 48, according to the National Alliance for Caregiving.

Because most people will be a part of caregiving in some form throughout their lifetime, this lesson introduces concepts from the Powerful Tools for Caregivers program, which is designed to provide caregivers with the tools they need to increase self-care and give them confidence in handling difficult situations, emotions, and decisions. *The Caregiver Helpbook*, listed in the resources at the end (or provided as part of an extension program), is full of resources that will help you maintain your physical and emotional health.

The life you have planned before or after you retire can change in an instant because of an accident or a health crisis. Soon you find yourself in the midst of doctors' appointments, lab testing, cancer treatments, rehab choices, possibly a long distance from the family home and with tremendous medical costs. This will also include working with other members of the family to discuss care responsibilities at a stressful time. It underscores the need for preparation and family discussions, including the affected loved one. Even if insurance will cover most of the expenses, there are still the extras, such as travel, hotel, and meal expenses.

Your caregiving might begin as simple phone calls to an elderly aunt that transpires into a full blown caregiving job, such as helping her make health-care decisions. A parent who had cancer has a relapse and must begin treatments again. You and your siblings are employed outside the home. How do you manage all this stress?

Managing Stress

Life brings positive or negative changes, which causes stress. Your attitude toward the care receiver as well as the caregiving situation will factor into how well you manage stress. If the relationship with the receiver has been difficult, caregiving could be a challenge.

Whatever the caregiving situation requires of you contributes to stress. Does your family member have dementia or physical limitations? Is there a mental disability or a combination of several things?

If you voluntarily take on a caregiving situation, you are making a choice. If you feel that you've "inherited" the job or that you "have to" be the caregiver since it's a family member (spouse, child, or in-law) then you will have different stressors. Good communication skills can help you work with your care receiver, other family members, as well as the medical professionals to be a successful caregiver.

Statistics show that caregivers who feel isolated or without adequate support usually experience a higher level of stress. Don't wait for others to volunteer for something; make a list of what others could help with and then let them help. One caregiver in north central Kansas felt guilty when her neighbor scooped snow out of her driveway for her. Try to move beyond guilt to thankfulness, acknowledging the neighbor's gift of love in a time of a husband's illness. Many times others don't know what to do to help out. Ask for help with simple housekeeping tasks, so you can spend your time with your family member.

As you travel along your caregiving path, you will start to recognize your various stressors and will need to determine a positive way to care for yourself during this situation. Consider this useful metaphor: Airlines always insist that in the event of an emergency, you should put on your own emergency oxygen mask before you put a mask on a dependent individual. Self-care is important for your well-being, and even a short break from caregiving can help you return to the situation with a refreshed attitude. Your care receiver also can use a break and may enjoy another's company periodically.

Some self-care suggestions include: get proper rest, exercise regularly, attend to your own health-care needs, and take time off doing pleasant and nurturing activities for yourself. Something as simple as asking someone to sit with your care receiver so you can attend church or get groceries would be an example of self-care. Make sure you regularly do something for yourself so your attitude can remain positive.

Proper diet, adequate sleep, and regular exercise are necessary for everyone, and even more so for caregivers. Exercise promotes better sleep, reduces tension, and increases energy and alertness. Find activities you enjoy and can do in shorter blocks of time. Maybe your care receiver would enjoy a simple stretching routine.

Incorporate walking into your routine whenever possible, because it is one of the best and easiest exercises for wellness. Walking 20 minutes three times a week is beneficial, but if you can't be away, do smaller increments of time to reach that 20-minute goal. If you don't feel like you can get away from the care receiver, use exercise tapes available from your library or borrow one from a friend.

Meditation is a stress reducer. Soothing music and deep breathing can calm you down. Even humor, when used correctly and not hurtfully toward the care receiver, can help reduce stress. Your heart is heavy and finding pick-me-ups can brighten your day.

Reframing your stress can also help you manage stress more productively. Make a list of the things you find most difficult and then ask yourself: Can I ignore this, or can I let it go? Can I change anything about this? If so how? If it can't be changed, can I change my perception of it? (*The Caregiver Helpbook*, pg. 35)

Another tool to relieve stress is to focus on your breathing. You will find as you focus on this breathing tool, you will be able to calm down. This gives your body something else to focus on besides your worries.

Breathing for Relaxation

Follow these steps:

1. Close your eyes. If that isn't possible, quietly become aware of your breathing.
2. Inhale to the count of seven, slowly and deeply. Exhale to the count of seven, slowly and deeply. Exhaling is "letting go."
3. Repeat — without forcing your breathing in any way. If your mind becomes distracted, refocus on your breathing.
4. Continue for one to two minutes or longer if you want. Notice how relaxed you feel.

Legal Issues

A legal checklist for caregivers from AARP lists six tips on how to protect your relative's legal rights and your own.

*Make sure you have the right documents. In addition to a will, your loved one will need a health care power of attorney (also known as living will) as well as power of attorney (POA) for financial decisions. While a living will is required for hospitalization and medical professionals help with that document, the financial power of attorney needs to be drawn up by a lawyer.

- Make a family plan. Discuss caregiving matters with all involved members of your family, and have the loved one put in writing who is responsible for which caregiving role. This isn't a legal document but will help make everyone's role clear.
- Organize important papers. Most people don't realize how many legal documents they already have, or how many they will need for matters that arise. Important ones include birth and marriage certificates, divorce decrees, citizenship papers, death certificate of spouse or parent, power of attorney, deeds to property and cemetery plots, veteran's discharge papers, insurance policies, and pension benefits. Organize these documents into files that are easy to navigate.
- Explore potential financial help. Investigate public benefits such as Social Security and Supplemental Security Income (SSI) disability programs, veteran's benefits, Supplemental Nutrition Assistance Program (formerly known as food stamps), Medicare, and Medicaid. The AARP Foundation offers an online tool, "Benefits QuickLink," to help determine if your loved one qualifies for 15 different government programs (*www.benefitscheckup.org/cf/snap.cfm?partner_id=22*). The National Council on Aging offers a similar online tool called "Benefits Checkup." (*www.benefitscheckup.org*)
  Also examine your loved one's private disability or life insurance coverage, their pension benefits, long-term care insurance, and employee health insurance policy to see what is covered, such as home health visits, skilled nursing, physical therapy, or any short-term assistance that could include a mental health therapist.
  If you have to take leave from your job, you are entitled to three months unpaid leave under the Family and Medical Leave Act from your employer and are guaranteed your job when you return.
- Think beyond your loved one. If your parent is unable to care for dependent grandchildren or an adult child with special needs, you will need to take care of that role.
- Look for tax breaks and life insurance deals. Keep all medical expense receipts for tax deductions. Your family member may claim federal deductions for many medical expenses, including hospital bed, wheelchair, out-of-pocket expenses not covered by health insurance (drug costs and copayments), remodeling the home to make it handicapped accessible, and respite care to give the main caregiver a break. Check the life insurance policy to find out if the policy makes accelerated death payments to help pay for long-term care. (*www.aarp.org/home-family/caregiving*)

Organizational Tips

While your life as you know it may change in an instant, as a caregiver you'll need to have some basic organizational skills. Be sure to ask questions of medical personnel if you don't understand a test or operation that your care receiver will be going through. Always date your notes and other information as this may become important for filing insurance claims and paying medical bills. Go back over notes and write down other questions to ask the doctors or health-care providers.

Questions and answers are how you learn about the health crisis you are experiencing with your care receiver, and you may need to be an advocate for them if they have communication issues. But if at all possible, let the care receiver do the asking so he or she still has some control in the situation.

You may consider setting up a Facebook page for your family or a Caring Bridge page (*www.caringbridge.org*) so your larger community of friends can stay updated on the care receiver's progress. It might be helpful to have a young family member be in charge of posting information to the Web, making that one less job for the caregiver.

In the end, your attitude or how you look at life will help you through this crisis. How do you see life, are you an optimist or a pessimist? Do you view life as opportunity for learning or something to just endure? Caregiving can be an extreme challenge, depending on the care receiver's condition. But your gift of care, whatever it may be now or in the future, can be enhanced by learning to manage your stress and use local resources along the journey.

Local Resources

Be sure to check with the local health department, hospital, medical clinic/doctors, and assisted living facilities in your community. You'll be surprised at what your local community can provide caregivers such as home health or respite care. Your church community, as well as the public library, will also be another resource for you. Helping agencies can link you with Meals on Wheels and transportation assistance. Personnel at these agencies can connect you to regional agencies, such as mental health centers and disease specific agencies. While it may seem you are alone in the sea of stress, others are willing to help if you ask.

This FCS lesson just skims the surface of caregiving needs; the authors suggest you check out *The Caregiver Helpbook* for more information. Your local library can assist you in using the computer to explore the resources used in collecting this material.

Resources

State agencies

Kansas Department of Aging and Disability — *www.ksadrc.org/Links.html*. Site has links for Kansas Area Agencies on Aging, Association of Community Mental Health Centers of Kansas, Veteran's Affairs, Kansas Attorney General, assistive technology, and much more.

Kansas Department of Health and Environment — *www.kdheks.gov*. One can locate public health service across the state on this site.

State Universities:

Kansas State Research and Extension's aging website — *www.aging.ksu.edu/p.aspx*

Kansas State University Center on Aging — *www.he.k-state.edu/aging*

National Extension site — *www.extension.org/family_caregiving*

Books:

The Caregiver Helpbook: Powerful Tools for Caregivers. Legacy Caregiver Services. Portland, Oregon, USA 503-413-8018, *caregiver@lhs.org*.

Women in the Middle, Their Parent-Care Years. Elaine Brody, 2004, Springer Series of Lifestyles and Issues in Aging.

Passages in Caregiving: Turning Chaos into Confidence. Gail Sheehy, 2010, G. Merritt Corp.

Authors also suggest the following website for a wealth of information on caregiving: *www.aarp.org/home-family/caregiving*.

Publications from Kansas State University are available at: *www.ksre.ksu.edu*

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