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Caregiving 101: On Being a Caregiver

Caregiving often creeps up on you. You start by dropping by your mom's house and doing her laundry, or taking your dad to a doctor's appointment. You find yourself doing the grocery shopping and refilling prescriptions. Gradually, you are doing more and more. At some point, you realize you have made a commitment to take care of someone else.

Sometimes, caregiving is triggered by a major health event, such as a stroke, heart attack, or accident. Maybe you suddenly realize that dad's memory lapses have become dangerous. Life as you know it stops, and all your energy goes to caring for your loved one. Caregiving has become your new career, and you adjust to a new normal.

The Caregiver Role

Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, grandchildren), friends, neighbors. Whatever your relationship with the person you're caring for, it's important that you add the title *caregiver* to the list of things you are. Without identifying yourself as a caregiver, you won't know to search for resources that can help you navigate this new role.

But caregivers play other roles as well. You may be employed full or part-time. You may be raising children, or be a volunteer, a spouse, have other family commitments. Adding caregiving to that list can easily lead to frustration and exhaustion. You might need to navigate social service systems, call doctors while you're at work, advocate for the care receiver, and take care of their day-to-day needs, while you try to do all of those same things for yourself and your family.

You are rarely trained to do the broad range of tasks you are asked to do as a caregiver. As a result, you may end up, for example, with back strain because you haven't had the benefit of training from a physical therapist on how to correctly

transfer someone from bed to chair, or wheelchair to car. Or you find yourself battling with your mother who has Alzheimer's because you have not learned the skills necessary to communicate with someone with a cognitive impairment.

Here are some of the common tasks caregivers do:

- Buy groceries, cook, clean house, do laundry, provide transportation
- Help the care receiver get dressed, take a shower, take medicine
- Transfer someone out of bed/chair, help with physical therapy, perform medical interventions—injections, feeding tubes, wound treatment, breathing treatments
- Arrange medical appointments, drive to the doctor, sit in during appointments, monitor medications
- Talk with doctors, nurses, care managers, and others to understand what needs to be done
- Spend time handling crises and arranging for assistance—especially for someone who cannot be left alone
- Handle finances and other legal matters
- Be a companion
- Be a (usually) unpaid aide, on call 24/7

What are all the things you do? Try making a list, both for your own clarification and for other family members who may not be aware of your efforts.

First Steps for New Caregivers

- It's easy to become overwhelmed as a new caregiver. Here are some steps that can help:
- Identify yourself as a caregiver
- Get a good diagnosis—from a specialist or geriatrician if necessary—of your loved one's health condition
- Learn what specific skills you might need to care for someone with this diagnosis (Caring for someone with Frontotemporal dementia, for example, is different from caring for someone with chronic heart disease)
- Talk about finances and healthcare wishes
- Complete legal paperwork, e.g., Powers of Attorney, Advance Directives
- Bring family and friends together to discuss care
- Keep them up to date on the current situation

- Identify resources, both personal and in the community
- Find support for yourself and your loved one
- Remember, you are not alone

Keys to Caring for Yourself

It's one thing to gear up for a short-term crisis. But it takes different skills to provide care over a longer period of time. You'll be more successful if you learn to take care of yourself, starting immediately. Some things to remember:

- You cannot be perfect
- You have a right to all of your emotions (See FCA Fact Sheet [Emotional Side of Caregiving](#))
- Depression is the most common emotion of long-term caregivers
- Set realistic expectations—for yourself and your loved one
- Learn about the disease and what you can expect
- Learn the skills you need to care for the care receiver and which ones you are or are not able to perform
- Learn to say “no” to things you cannot do
- Learn to accept help from others
- Build resilience
- Identify your button-pushers/stressors
- Identify your coping skills
- Remember the big three for successful coping:
 - **Eat right**—good nutrition as opposed to stress-snacking. Limit alcohol and other drugs
 - **Exercise**—it may be hard to find time but it's the best cure for depression and increases your endorphins (“good” coping hormones)
 - **Sleep**—7-8 hours is hard to get, but essential. Admit when you are experiencing burnout and get help

Most importantly, remember that taking care of yourself is as important as taking care of someone else.

The ‘IRS of Caregiving:’ Information, Respite, and Support

⇒ **INFORMATION**

The first stages of caregiving are the most challenging. This is when you are least informed about what's needed and expected, and when you feel the most insecure and uncertain.

- In addition to information about the disease/disability your loved one is dealing with, you need to understand his or her medications and medical interventions. (See FCA Fact Sheet [Caregivers Guide to Medications and Aging](#))
- What knowledge/skills will you need to be able to care for him or her? Where can you get trained to do the tasks required? How can you learn to successfully:
 - Feed, bathe, groom, or dress someone?
 - Handle toileting or deal with incontinence?
 - Handle a complicated medication schedule?
 - Transfer someone or help them walk?
- How does this disease progress and how will that effect the care receiver's ability to take care of him or herself?
- What are the care needs now and what are they likely to be in the future?
- What are the physical limitations that the care receiver has now or will have?
- What are the cognitive changes you can expect?
 - Are there predictable behavioral changes that go along with them?
 - How do I handle these changes?
 - If you are caring for someone with dementia, for instance, you need to learn the strategies for communication that will make you more successful and increase cooperation.
- What is the financial situation? (See FCA Fact Sheet [What Every Caregiver Needs to Know About Money](#))
 - How much money is available to help with care?
 - Who can access it (is there a Financial Power of Attorney in place)?
 - Are there debts or other constraints on using the money?
- What legal matters should you know about? (See FCA Tip Sheets [Legal Planning for Incapacity](#) and [Where to Find My Important Papers](#))
 - Is there a Will? A Trust?
 - Has the Medical Power of Attorney been completed (also called Living Will)? (See FCA Tip Sheet, [Advanced Health Care Directives and POLST](#))
 - Do you have a Release of Information signed and filed with the care receiver's doctor(s)?

You might not be aware of community caregiving resources, but they are there to help you. You can find help in most communities for transportation, home delivered meals, day care programs, home repairs, and more. To learn about them, contact your local Area Agency on Aging (AAA) and find out what's available locally—not only for your loved one, but also for yourself. (In many communities, AAAs can be reached by dialing 211). There may be benefits that you haven't thought about—ask about Title III E funding, part of the Older Americans Act specifically for caregivers. There may be Veterans benefits. Other benefits can be found at Eldercare Locator, or FCA's Family Care Navigator.

⇒ **RESPIRE**

Caregiving is often a 24/7 job, and everyone needs a break sometimes. Getting away can give you perspective and remind you that there's a world outside. Taking a respite break from caregiving can give you a chance to connect with others, share, laugh, catch up, renew. But it can also be a time for just doing things that are relaxing for you, such as reading a book without interruption, taking a nap, or going for a walk. This break is a necessary step in taking care of yourself so that you can care for someone else.

Respite can take many forms, from going away on a mini-vacation to having someone in your home for a few hours so you can run errands or get to the doctor yourself. A local adult day care program may offer enough hours of care—including transportation—so that you can go to work or attend to your other needs and interests. Some residential facilities also offer temporary respite. There may be funds available through your Area Agency on Aging as well as organizations in your community that can help you to get the break you need (also available through the Veteran's Administration for those eligible). Faith communities, disease-specific organizations, and your network of friends might be able to help.

At first, it may not feel easy to take a respite break. First, there is our own internal reluctance to leave a loved one, particularly if he or she feels abandoned if you leave. Or there is the fear that something will happen while you're away and only you know how to care for him or her correctly. You might feel guilty and not be sure you have the right to have a good time if your loved one is suffering. You may be concerned about the cost. But remember, you must care for yourself, too.

⇒ **SUPPORT**

You can't do it alone! And, like respite, getting support for your caregiving situation will help you take better care of yourself. The longer you are a caregiver, the more isolated you can become. How many times can you say, "I can't get together with you" before people stop calling? But this lack of social interaction will lead to poorer health for you. One reason caregivers don't get the help they need is that taking care of yourself feels like just "one more thing you have to do."

But we all need someone to talk to. Special caregiver support groups in your community or online can help to reduce the feeling that you're all alone and help you learn coping skills from others who are in similar situations. (See FCA Fact Sheet [Taking Care of YOU: Self-Care for Family Caregivers](#).)

Adding stress to an already difficult situation, caregiving can also create family discord, particularly if you feel you're not getting the help and support you need from members of your own family. Resentment can build on all sides. If you are dealing with family conflict, it might help to have a meeting. (See FCA Fact Sheets [Holding a Family Meeting](#) and [Caregiving with Your Siblings](#))

Asking for Help

Most of us find it hard to ask for help. About 50% of caregivers get no outside help at all. When someone asks if there's anything they can do to help, most of us usually say, "Oh no, that's OK, we're doing fine." When you're a caregiver, it can be even harder. Whom can you call and what can you ask them to do? Learning to accept help early in your transition to being a caregiver will make it easier down the road.

Little things on a regular basis can mean a lot. Maybe someone would bring an occasional meal or dessert. Having someone help with household chores can be an opportunity to socialize as well as get things done. Maybe someone can just come and sit with your loved one so you can run to the grocery store. Make a list of things that you need help with. Post it on the refrigerator. If someone asks to help, show them the list and let them pick something they'd like to do. That way they're more likely to enjoy the task. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal prep instead of a ride to an appointment.

Taking Care of YOU

Caregiving has many challenges and also many rewards. But you need to honor your own needs as well as commit to caring for someone else. That's the only way you will be able to sustain your patience and your caring and be successful over time. There are many things to learn and most caregivers are just "making it up" as they go along. Getting information and training will help you feel confident about the many tasks you perform. Information is available online, at disease-specific websites, at Family Caregiver Alliance, through your medical providers, Area Agencies on Aging, some employee assistance programs, support groups, senior centers, and your community. Start with saying "I am a caregiver and I need help."

Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's, and other debilitating health conditions that strike adults.

FCA CareNav: www.fca.cacrc.org/login

Services by State: www.caregiver.org/connecting-caregivers/services-by-state

FCA Fact Sheets: www.caregiver.org/fact-sheets

ElderCare Locator

A public service of the Administration on Aging, U.S. Department of Health and Human Services, eldercare.acl.gov.

This fact sheet was prepared by Donna Schempp, LCSW, and reviewed by Family Caregiver Alliance. Funded by the California Department of Health Care Services. © 2016 Family Caregiver Alliance. All rights reserved.

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