Who is a Family Caregiver?

A family caregiver is someone who is responsible for the well-being of another person. That person is often an elderly or disabled parent, but may also be a disabled spouse or child, an extended family member, frienc, or neighbor.

Family caregivers are referred to as informal caregivers, because they are not paid for the service they provide. In fact because their caregiving efforts are not recognized as formal work, family caregivers can be tough to identify. Often they do not publicly acknowledge their caregiving role.

You might be surprised to learn that most Americans will be family caregivers at some point during their lives. Some will serve as caregivers for long periods of time, others just briefly. Some will be engaged in caregiving tasks from afar, others will choose to live with their care recipients. Many will struggle to balance caregiving and job responsibilities and to cope with stress and finances.

Did you know?*

- An estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the prior 12 months.
- Nearly 1 in 10 caregivers is 75 years of age or older (7 percent).
- 82 percent of caregivers care for one person who is likely either living with the caregiver or living within 20 minutes of the caregiver.
- 60 percent of caregivers are female. The typical caregiver is a 49-year-old female caring for a 69-year-old female relative, most likely her mother.
- 40 percent of caregivers are male.
- Six in 10 caregivers report being employed at some point in the past year while caregiving. Among them, 56 percent worked full time, and on average they worked 34.7 hours per week.
- Caregivers have been caring for four years on average, spending 24.4 hours per week helping with activities like bathing, dressing, housework, and managing finances.
- 32 percent provide at least 21 hours of care a week, on average providing 62.2 hours of care weekly.
- 38 percent of caregivers report high emotional stress from the demands of caregiving.

*Source: Caregiving in the U.S. 2015; National Alliance for Caregiving in collaboration with AARP, Archstone Foundation. Eli Lilly, Home Instead Senior Care, MetLife Foundation, Pfizer, UnitedHealthcare, and the Family Support Research and Training Center in conjunction with the University of Illinois at Chicago, 2015.
Caregiver Roles and Responsibilities
(To help you determine if it is time to get more involved helping a loved one)

Have you ever pondered all that caregiving entails? Many people underestimate what is involved in providing compassionate care. People tend to think about the more tangible aspects of caregiving—the tasks involved—because those concerns are most often addressed in articles and literature.

According to the Pfizer Journal entitled A Profile of Caregiving in America (2005), more than 80 percent of caregivers provide assistance with daily living activities, such as providing transportation, shopping for groceries and other essentials, housekeeping, managing finances, preparing meals, dispensing medications, and more. In addition to performing tasks, caregivers also serve in many different roles. Some of the more common roles include:

- **ADVISOR** – Offering recommendations to help a loved one identify potential challenges, talking about concerns, sharing information, and considering alternatives that may help to maximize his or her independence and quality of life.
- **ADVOCATE** – Looking out for a loved one’s best interests as an authorized agent (e.g. Power of Attorney). Ensuring the person you serve gets the information, care, support, and treatment he or she needs and deserves.
- **COORDINATOR** – Arranging for services, such as professional caregiving, physical therapy, lawn mowing, snow removal and heating/air conditioning repair, scheduling appointments, coordinating deliveries, helping to facilitate end-of-life planning, and more.
- **EVALUATOR** – Assessing a loved one’s ability to live independently, handle his or her own personal care, manage medications, operate a motor vehicle, and more. Also, identifying and evaluating appropriate programs and services that best match a care receiver’s needs and wishes.
- **MEDIATOR** – Helping family members and others communicate with health care and social service providers, make decisions, and resolve issues in a positive and helpful manner.
- **PROTECTOR** – Taking charge when necessary to help ensure the safety and well being of a loved one.
- **PROVIDER** – Providing assistance when a loved one is not able to care for him- or herself due to physical or cognitive limitations. Assistance often addresses the following types of needs:
  - **EMOTIONAL** – Listening and responding to concerns, providing encouragement and moral support, and simply “being there” for someone.
  - **FINANCIAL** – Organizing bills, writing checks, balancing the checkbook, and providing money to help cover expenses.
  - **PHYSICAL** – Assisting with daily living activities, including personal care, household chores, meals, driving, etc.
  - **SOCIAL** – Maintaining regular contact and minimizing isolation and boredom through relationships and keeping loved ones “in the loop.”
  - **SPIRITUAL** – Helping people find meaning and purpose in life, maintaining hope, coping and finding peace through prayer, meditation and cultural, and religious preferences.
10 Considerations to help you determine if it might be time to get more involved and help a loved one address challenges he or she may be facing.

Please rank each item from 1 to 10, 1 – not a concern, 5 – starting to be a concern, and 10 – a major concern

1. **MEDICAL CONDITION** – Has your loved one been diagnosed with a disease, illness, or other medical condition that could impact his or her ability to function in daily life?

   - 1
   - 5
   - 10

2. **DRIVING** – If your loved one drives, is there reason to believe he or she poses an above average risk of being involved in an accident? How are your loved one’s vision, reflexes, and ability to respond in unexpected situations?

   - 1
   - 5
   - 10

3. **FOOD / NUTRITION** – Is your loved one eating balanced meals? Is his or her weight stable? Does he or she have a reasonable variety of food in the refrigerator with future expiration dates?

   - 1
   - 5
   - 10

4. **HYGIENE** – Does it appear your loved one is bathing and brushing his or her teeth regularly? How are his or her overall appearance, grooming and ability to match clothing compared to prior years? Are the bed linens and towels fresh? Does the soap in the bathroom appear have been used recently?

   - 1
   - 5
   - 10

5. **BEHAVIOR** – Does your loved one seem anxious or irritable? Does being away from home make him or her uncomfortable? Does he or she seem depressed? Is there inconsistency in the things he or she says? Does your loved one remember names, places and current events?

   - 1
   - 5
   - 10
6. DAILY TASKS – Are basic tasks, such as getting ready to go out or preparing a meal or shopping, overly challenging, frustrating, or time-consuming for your loved one? Does their living space appear clean? Is there a concern about hoarding?

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7. MEDICATION – Can your loved one manage his or her medications properly including dosage, frequency and changes to prescriptions? Does your loved one understand why he or she is taking the medications? Are prescriptions getting refilled in a timely fashion?

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8. FINANCES – Does it appear your loved one is capable of making sound financial decisions? Is he or she able to manage personal affairs and finances? Does he or she have a reasonable amount of cash on hand? Have there been any unusual purchases or suspicious expenses or investments?

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9. MAIL – Is the mail stacking up? Is there reason to suspect any past due or delinquency notices? Does your loved one appear to be a target for solicitation and sweepstakes offers?

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10. SAFETY – Is your loved one careful about turning off appliances (e.g. stove, coffee pot)? Does he or she ever carelessly leave candles or cigarettes burning? Are sharp objects properly put away? Are the stairs and hallways unobstructed? Are the doors and windows locked? Is he or she able to easily locate the keys? Is there any reason to believe someone is trying to control or take advantage of him or her?

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Resources for Caregivers

Visit the following sites to familiarize yourself with resources for family caregivers:

Gwinnett Senior Services [http://www.gwinnetseniorservices.com](http://www.gwinnetseniorservices.com)
Gwinnett County Senior Services provides a variety of programs and services for our seniors, designed to enhance the quality of their lives and maintain their independence. These services also assist the families of seniors with their caregiving duties or call 678.377.4150.

ElderCare Locator [http://www.eldercare.gov/](http://www.eldercare.gov/) or call 1.800.677.1116

AARP Caregiving Resource Center, Information, tools and tips for caregivers
[http://www.aarp.org/home-family/caregiving/](http://www.aarp.org/home-family/caregiving/)

Family Caregiver Alliance. Family Caregiver Alliance supports and sustains the important work of families nationwide caring for loved ones with chronic, disabling health conditions.
[https://www.caregiver.org/](https://www.caregiver.org/)


Caregivers' Resources from USA.gov. Find a nursing home, assisted living, or hospice; check your eligibility for benefits; get resources for long-distance caregiving; review legal issues; and find support for caregivers.

Next Step in Care. Provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.


The Caregiver Action Network is the nation's leading family caregiver organization working to improve the quality of life for the 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. It is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.
A Caregiver's Bill of Rights

By Jo Horne

I have the right:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.

To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed, and express other difficult feelings occasionally.

To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer need my full-time help.

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.
Know that you cannot be discriminated against because of your caregiving role

1. Understand your company's benefits and policies. More companies offer progressive benefits to help employees caring for children and other family members. Benefits may include help finding resources, lunchtime seminars, subsidized back-up care, flextime, and counseling services. Check with your Human Resources department to learn if your company offers any benefits.

2. Know that you cannot be discriminated against because of your caregiving role. The federal Equal Employment Opportunity Commission has an article about your rights.

3. Understand how the Family and Medical Leave Act can help you. Typically, employers with 50 or more employees must comply with FMLA.

4. Communicate effectively with your boss. Explain the caregiving situation, how you plan to manage it, and ask for feedback. You may start a discussion this way: “My father is not doing well and is now living with me. I have hired help and organized my family to assist to ensure my father is okay while I am here at work. It’s possible that I may encounter a crisis because my father’s health is unstable. What would be the best way for me to communicate and handle any crisis?” You also may want to ask your boss for suggestions on how to communicate this situation with your coworkers.

5. Ask co-workers if they have cared for an aging relative while employed with your current employer or know of others who have. Ask for suggestions on how they managed the situation.

6. Know who can help (professionals, family members, friends, neighbors) and how they can help. Ask for and accept the help. A geriatric care manager can be a terrific investment to help find resources and oversee care. You can find more information with a visit to the National Association of Professional Geriatric Care Managers.

7. Create a back-up plan. Ask yourself all the “What If?” questions you can think of. When developing your plan, ask for feedback from family, your friends, your support group, your caregiving coach, and a geriatric care manager. If appropriate, co-workers and management may be able to offer insights.

8. Set limits with family members and carees about your availability during work hours. Perhaps you determine you can be available during your lunch hour to field calls or for a few minutes during the afternoon. (Of course, during a crisis—and you may have to define “crisis” as others’ definitions may differ from yours—you are always available.)

9. Remember the Three Be’s of Caregiving (Be Prepared, Be Honest, Be Well). And, consider writing a Caregiving Mission Statement.

10. Keep two journals—one for your feelings and one about your caree’s needs, medications, treatments, likes/dislikes, and care tips. You will come to value both as treasures.

11. Forgive yourself for any bad days; give yourself a fresh start the next day. In addition, think ahead about five years. When you look back to now, what actions and decisions will make you proud?
Managing someone else’s money series

Guides that help family members and other caregivers understand their role as financial caretaker, providing tips on making financial decisions for someone else as well as protecting assets from fraud and scams. Titles include:

1. Help for Guardians of Property and Conservators
2. Help for Agents under a Power of Attorney
3. Help for Representative Payees and VA Fiduciaries
4. Help for Trustees under a Revocable Living Trust

Money Smart for Older Adults: Prevent Financial Exploitation

Guide providing information on common frauds, scams and other forms of elder financial exploitation. Gives steps older persons and their caregivers can take to avoid being targeted or victimized.

Protecting Residents from Financial Exploitation

A manual for assisted living and nursing facilities. This manual helps family caregivers and assisted living service providers prevent, recognize, and report elder financial exploitation. It provides a detailed list of warning signs of financial abuse.

Order/view publications here: http://promotions.usa.gov/cfpbpubs.html (roll down to “special populations” listings). This web site provides publications in print and online (both free of charge).

Additional Financial Information/Resources:

Veteran Resource Center – serving all Gwinnett County Vets and families
750 S. Perry Street, Suite 300, Lawrenceville 30046 Phone: 770.828.8652
Tuesday, Wednesday and Thursday – 9:00am to 4:00pm

www.Medicare.gov Federal Government Medicare website

www.ssa.gov Social Security Administration website

www.benefitscheckup.org Answer a series of questions to help identify benefits that could save you money and cover the costs of everyday expenses.
Notes To Help You Be A Better Prepared Caregiver When Disaster Strikes

1. Prepare Home and an Away To-Go kit for you and your caree to be able to take care of yourselves. (See resources on tack for suggestions for kit items.)

2. Make sure you are trained on your caree's equipment intimately, know how to break it down and put it back together again.

3. Create a complete detailed medical document of your caree which includes their diagnoses(is), medicine, hardware/software needs, and personal assistance that they would need on a daily basis.

4. Make your plans to be flexible for the many types of disaster that can occur.

5. Get a medic alert bracelet with the text noting that you are a caregiver for someone who has (fill in the blank).

6. For every aspect of the emergency plan you create for your caree, create two more: one as an alternative and the other when the first two fail.

7. Make sure you have identified at least three other people (trained) who can fill your caregiving role in case you are caught on the other side of town or incapacitated for some reason when a disaster strikes.

8. Understand that when you are with your caree you are the “first” responder on the scene when a disaster occurs.

9. Reach out to your local Fire Department, Emergency Management Office and/or Health Department and ask them to connect you with emergency planning resources/tools that would be catered to the specifics of your caree’s situation.

10. Make sure the nursing home, assisted living facility, personal care home, therapy, caregiving assistance entities that you work with also have emergency preparedness planning that covers your caree...and if not make sure one is created to your liking.

11. Take a CPR Course.

12. Take a community CERT (Community Emergency Response Team) course. This does not mean that you have to sign up and help them necessarily; but its a great place to learn how to put out small house fires, address utility problems, and very basic disaster protection. (See for more information: http://www.gwinnettcounty.com/portal/gwinnett/Departments/Police/EmergencyManagement/VolunteerandTraining/CERT)

13. Work with your caree to make sure they know what to do and understand its importance. If they don’t have the capacity to participate then write this aspect into your plans.

14. Don’t forget to make plans for yourself, loved ones and pets as it will be difficult for the caree if they have to worry about you too!

By: Laura George, Emergency Management Disability Liaison 10/20/14
For More Information See These Resources

For other counties in the Atlanta region go to [www.agewiseconnection.com](http://www.agewiseconnection.com) or call the AgeWise Connection at 404.463.3333 to speak to a certified information and referral specialist.

**US DHHS AOA (Administration on Aging)**
National Family Caregiver Support Program. Emergency Readiness for Older Adults and Caregivers
http://www.aoa.gov/AoA_Programs/HCLTC/Caregiver/docs/Just_in_Case030706_links.pdf

**CDC (Centers for Disease Control)**

**National Center on Caregiving**
Emergency Preparedness on Caregiving
https://caregiver.org/emergency-preparedness-checklist-caregivers

**US DHHS ASPR (Assistant Secretary for Preparedness and Response)**
Public Health Emergency. Disaster Preparedness for Family Caregivers Webinar (Dated 4/16/14)

**NextAvenue**
Why Caregivers Need to Plan for the Worst. Whether your loved ones live alone or in a nursing home, be ready to help them in case of disaster and reduce stress by preparing for trips to the hospital in advance, by Sherri Snelling, 4/22/13
http://www.nextavenue.org/article/2012-07/why-caregivers-need-plan-worst

**Rural Caregivers/Perdue University**
Emergency Preparedness (Note: This is a list of documents relating to more to the topic of persons with disabilities)
https://engineering.purdue.edu/~bng/Caregiving/emergency.html

**Aging and Disability Resource Center**
This site also has a full description of Veterans Services. It includes fact sheets on Medicare, Medicaid, etc and many are available in several different languages. Includes links to many other agencies. https://Georgiaadrc.com

**Alzheimer’s Association**
www.alz.org