

# CARE for the FAMILY CAREGIVER: A Place to Start

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THE WHITE HOUSE  
CONFERENCE ON AGING  
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# CARE for the FAMILY CAREGIVER: A Place to Start

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**Know** 

that as a caregiver, you are not alone. In fact, experts estimate that more than **44.4 million** Americans are caregivers to adult friends or family members.

**CARE for the FAMILY CAREGIVER**

# Introduction

Welcome to the *Care for the Family Caregiver: A Place to Start*. We hope you find this booklet informative and helpful.

This booklet serves family caregivers. The term “family caregiver” applies here to a person who cares for relatives and loved ones. The care recipient might be a member of the caregiver’s *family of origin*, or his or her *family of choice*, such as a special friend, neighbor, support group member or life partner. In either instance, the term “family caregiver” in this booklet refers to a non-professional who provides unpaid care for others in the home.

## Facing the call to caregiving

Throughout our lives, many of us are asked to care for another person—to become *family caregivers*. Perhaps you were called to the task after a loved one’s illness slowly progressed to the point where he or she needed help at home. Maybe someone needed your help suddenly, after a tragic accident. Your caregiving responsibility may be short-term, long-term or indefinite. Whatever the circumstances, the road ahead on your caregiving journey may seem long and uncertain.

Know that you are not alone. Although you may feel isolated, together family caregivers are part of a larger community. Did you know that more than 44.4 million people in the United States, or 21% of the population, serve as unpaid caregivers to an adult family member or friend?

If you look around, you might discover:

- \* Your coworker cares for an elderly parent at home.
- \* A family friend might be a caregiver to a spouse or life partner with a serious illness, such as cancer, and is dealing with end-of-life issues.
- \* Your pastor/spiritual advisor might be serving as a caregiver to his developmentally disabled daughter in addition to his responsibilities to his congregation.

Each caregiver situation is unique, yet all share universal experiences that encompass physical, emotional and spiritual—as well as economic and legal—concerns.



## The **Caregiver** **Resource Guide**,

found at the back of this booklet, contains a list of government and private resources that can help with information on caregiving, housing, aging, mental health, respite and hospice care, and legal and financial advice.

### **What you will find inside this booklet**

This booklet provides an overview of the following important topics:

- \* The caregiving journey, told through family caregiver stories
- \* The basics of family caregiving
- \* Caregiving tips
- \* Caregiver training
- \* Caring for yourself
- \* Legal and financial issues to consider
- \* Where to turn for help

### **How to use this booklet**

This booklet is designed to give you an overview of the basic aspects and issues involved with caregiving. It is not an exhaustive report on the subject. Rather, it provides basic information about many important and universal aspects of caregiving.

Feel free to read this booklet all the way through, front to back. Or, use the Table of Contents to guide you to those parts that may be most helpful to you. You may want to start a file or designate a special place in your home for caregiving resources, including this one.

You may find a topic in this booklet that you have not yet considered. Perhaps you have not yet encountered the financial aspects or legal issues involved in family caregiving. You may find that simply recognizing and anticipating these and other issues will help you take the first steps in determining a plan of action.

## It's OK to ask for help

Many government programs, advocacy groups and agencies are working to educate and support family caregivers on a national level and in local communities. The Caregiver Resource Guide in the back of this booklet provides an organized list of programs you can refer to for help and additional information. You may want to also add local resources on the Notes page.

Caregiving presents considerable challenges—physical, emotional and economic. There is no reason to suffer in silence. If you take away one thing from this booklet, remember, *it's always OK to seek and ask for help*. Getting help can enable you to become a better caregiver.

Do not feel guilty, or like you have failed, if you need assistance caring for a family member or friend. Help is available and you are encouraged to seek it out—even if you don't feel you need it. There are services, information, training and counseling that can help you provide better care to your loved one. It can also help you protect your own health and financial future.

The process of educating and preparing yourself may help you reduce stress and better cope with the many challenges of caregiving. This booklet is designed as a place to start.



## The Voice of the Caregiver

The life of the person you are caring for has likely changed forever. Likewise, yours may change, perhaps dramatically, as you adjust your already busy life to include caring for another person. You may feel socially isolated, as if you are the only person in the world facing the struggles of caregiving.

However, if you reach out during this time for help and information, you might discover that the stories of other caregivers mirror your story. Start by reading the caregiver experiences described in this booklet or joining a support group. Others in similar situations may be able to voice feelings you are unable to describe. Many people find comfort in that, and in knowing they are not alone.



## Caring for a spouse: Nancy's journey

**N**ancy and her husband had looked forward to retirement. After a lifetime of working and raising a family, Nancy was ready to slow down and finally have some time for herself. She planned to visit her grandchildren and pursue her favorite hobbies.

Nancy's retirement, however, turned out to be short-lived. Her husband suffered a stroke and came home from the hospital with partial paralysis. He improved little by little, but still needed help with the activities of daily living, including dressing, bathing and eating. He also required intensive physical and speech therapy several times a week.

Nancy now found her days filled with endless tasks and appointments. This left her feeling overwhelmed. Her daughters were busy raising young children of their own, and she was reluctant to ask for help. She also felt guilty for resenting the loss of the leisure time she had finally come to enjoy. Despite the daily struggles, she managed to find moments of joy in the quiet time spent with her husband. \*





## Lives interrupted: A family changes forever

In an instant, Nick's family changed forever when a car accident claimed the life of his wife and left his 15-year-old son with a serious spinal cord injury. He found himself suddenly responsible for everything from housework to looking after his two daughters who missed their mother terribly.

His son needed constant care. He required oxygen as well as special equipment to transfer him from his bed to a wheelchair. A home health care aide came for several hours a day during the week, but Nick was left alone many evening and weekend hours to wrestle with complicated medical equipment.



Before the accident, Nick's family depended on two incomes. Even with Social Security disability to help pay for his son's expenses, money was tight. Most weeks, he barely got by.

Dreams for his son's future, a promising athlete, were lost. Nick's wife, his high school sweetheart, was gone. Even still, the enormous task of caring for a disabled son and running his household left no time to acknowledge his grief. Eventually, Nick joined a support group, where he was able to face his grief, and where he came to realize and appreciate how their tragedy had helped deepen his relationships with his children. \*



## Cecile and Agnes: Facing the golden years together



**A**t first, spunky, active 95-year-old Agnes was simply forgetful. She left her keys, handbag and glasses in the synagogue, at the senior center and at the table of her favorite restaurant. When her 75-year-old daughter Cecile broke her hip several years earlier, Agnes had moved in with her. Mother and daughter anticipated that one day Agnes would be the one to require care. They did not count on Agnes suffering a rapid decline from senile dementia. Both feared leaving home and vowed to take care of one another.

With health problems of her own, Cecile found herself struggling to care for her elderly mother. Agnes was physically healthy for her age, but her mental capacity deteriorated quickly. Their friends seemed to know about Alzheimer's disease, but other dementia was poorly understood. Agnes

“looked fine” to others. Well-meaning comments, such as, “At least it’s not Alzheimer’s,” were hurtful to Cecile and left her feeling isolated.

Perhaps the worst part of Cecile’s situation was the change in her relationship with her mother. Within a year, Cecile found her to be a virtual stranger who no longer recognized her. Cecile had in essence lost the mother she had known her entire life. Despite the difficulties, Cecile was grateful to be able to look after her mother in her time of need. \*

One in five   
Americans, or  
21% of the US  
population, serves  
as a caregiver.

## The Context of Caregiving

### What is a caregiver?

Society, advocacy groups, the health care industry and the government all have definitions for “family caregiver.” In simple terms, a family caregiver is someone who is responsible for attending to the daily needs of another person.

Family caregivers are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend.

Family caregivers are sometimes described as “informal,” a term professionals use to describe those who care for family members or friends in the home, typically without pay. “Formal” caregivers, including home health care providers and other

professionals, are trained and paid for their services. Some formal caregivers are trained volunteers associated with an agency. This booklet focuses on informal, family caregivers.

### The face of the family caregiver

Caregivers are all around us. More than 44.4 million Americans serve as informal caregivers to people aged 18 years and older who live in the community and require help. Spouses, adult children, other family members, partners, friends and neighbors all serve as unpaid, informal caregivers. Most caregivers (83%) are related to the care recipient.

Studies have shown that caregivers are all ages and come from all walks of life. The average age of a caregiver providing care to an adult is 46. More than half of all caregivers are between 18 and 49 years old.

Although the majority of family caregivers are women, more and more men are becoming caregivers. The care of a family member, in the absence of a spouse, most often falls on the shoulders of a daughter or daughter-in-law. Women on average spend 17 years of their lives caring for children and 18 years

The typical   
American  
caregiver is a  
46-year-old  
woman with some  
college education  
who works and  
spends 20 or more  
hours a week caring  
for her mother.



caring for elderly parents. However, studies in the past decade have shown increases in the number of male caregivers. For example, a recent survey found that 39% of caregivers who participated in the study were men. Clearly, caregiving is no longer only a women's issue.

Some differences have been reported in caregiving among different ethnic groups. Experts have noted that cultural and ethnic differences may influence expectations on family caregivers.

## What do family caregivers typically do?



In the 2004 Caregiving in the United States survey by the National Alliance for Caregiving and AARP, caregivers reported helping the care recipient with the following:

1. Transportation
2. Grocery shopping
3. Housework
4. Managing finances
5. Preparing meals
6. Helping with medication
7. Managing services

Half of all caregivers also reported assisting with the difficult tasks associated with personal care, including:

1. Getting in and out of bed and chairs
2. Getting dressed
3. Helping bathe or shower
4. Getting to and from the toilet
5. Feeding the care recipient
6. Dealing with incontinence and diapers

Care recipients facing terminal illness have special needs. If you are caring for someone at the end of his or her life, seek help with medical, financial and legal issues. You may choose to contact your local or national hospice program for more information.

### **Family caregivers: The backbone of long-term care**

It is a myth that most of our nation's elderly are cared for in nursing homes or health care institutions. Family members and friends primarily provide 80% of the long-term care at home in the United States.

Caregiving delivered via family and friends results in significant savings to the government, health care institutions and agencies that would otherwise be responsible for delivering care. In fact, the contributions represented by the care delivered by informal and family caregivers add up to \$257 billion each year.



### **“ My husband’s elderly mother**

came to live with my family last year. We have five children and it’s a tight fit in our small city apartment. However, we both value strong family ties and a commitment to care for one another. My husband and older children try to help, but I handle most of her care. It’s difficult, but the right thing to do. ”



**My brother's schizophrenia** was diagnosed when he was in his mid-20s. He spent several years homeless and in and out of hospitals. When he was finally stabilized on medication, he came to live with my family. I have looked after him ever since. Most people think of caregivers as those who care for elderly parents or spouses. However, those with serious, chronic mental illness require special long-term care, too.



### Who are care recipients?

In the context of caregiving, care recipients are primarily defined as adults aged 18 or older who require regular help with one or more activities of daily living (ADLs). These may include basic activities, such as bathing or dressing, or medical care requiring specialized equipment in the home.

“Grandparent caregivers” raising grandchildren may also qualify for government and private agency aid programs. These family caregivers have special legal needs to protect their rights and those of their grandchildren.

Virtually any illness, whether acute or chronic, or injury may result in a person requiring a family caregiver. Some people may require temporary, long-term or indefinite care.

Health conditions that commonly lead to the need for a caregiver include:

- \* Chronic brain disorders, such as dementia, Alzheimer's disease, and Parkinson's disease
- \* Traumatic brain or spinal cord injury
- \* Multiple sclerosis
- \* HIV/AIDS
- \* Cancer
- \* Cardiovascular diseases such as stroke or heart attack
- \* Chronic diseases associated with ongoing disability, such as diabetes and severe arthritis
- \* Mental health and psychiatric disorders
- \* Developmental disability



## The Graying of America

People aged 65 and older are among the fastest growing segment of the US population. Nearly one-quarter of Americans today are aged 54 or older, and one-third are older than 45 years. In addition, we're living longer than ever before. The number of Americans aged 85 or older increased by 29% between 1990 and 2000.



## Trends in caregiving

The American population is aging and “baby boomers” are moving closer to the age of 65. This “graying of America” is expected to substantially increase the need for at-home family caregivers in the coming years.

The increase in the elderly population, coupled with the need to care for them, has led to the recognition of family caregivers in a more formal sense by the health care industry, government and the community. As a result, there has been a steady rise in the number of advocacy groups and government programs (such as the National Family Caregiver Support Program) available to help family caregivers with counseling, education, training, legal and financial needs. See the Caregiver Resource Guide at the end of this booklet for a comprehensive list of resources available to family caregivers.

Respite for family caregivers has also gained attention in recent years. Respite is a short period of rest or relief. This

may be an afternoon, a day, or even a week off from caregiving responsibilities, typically provided on a regular basis by a home health care aide or provider. Respite may be delivered in the caregiver’s home or at a facility. Examples include adult day services or out-of-home respite programs, some of which are offered by nursing homes for a fee.

Studies show that regular respite care relieves stress and promotes a family caregiver’s overall health and well-being. In addition, it can also improve the caregiver’s ability to provide care. See the Caregiver Resource Guide at the conclusion of this book for a list of respite care resources. Also check with local aging and disability resources for respite services in your community.

## Helpful Tips for Family Caregivers: A Place to Start

Caregiving requires an enormous physical and emotional commitment, as well as some basic skills. The pages that follow provide tips and information on where to start.

### *Create a safe environment at home.*

Conduct a home safety inspection of your loved one's home or your own if you are caring for someone there. For example, check for adequate lighting, install grab bars in the bathroom and hook up a cordless phone for emergencies.

Home safety checklists are available on the Internet and from the AARP. (Go to [www.aarp.org](http://www.aarp.org), and look for safety checklist information.)

### *Get caregiver training.*

Seek out caregiving training. (See the Caregiver Training section that follows.) For example, learn the correct way to transfer a loved one from a bed to a wheelchair. This can help you avoid serious injury to yourself and the person for whom you are caring.

In addition, learn how to properly bathe someone with mobility problems. This can reduce the risk of hospitalization for chronic sores and infections.

### *Maintain medical records.*

Keep a current, complete list of all medications and physicians, along with notes on medical history. Be sure to take this if you accompany your loved one to doctors' visits.

Most care recipients (85%) take at least one prescription drug. It's important to keep a list of all medications the care recipient is currently taking. Be sure to also record the dosage or strength, such as 10 mg, and how often it is taken, such as twice a day. A drug regimen may change often, so be sure to make regular updates.

### *Learn about the disease.*

Find out all you can about the disease the care recipient has, its treatments and the prognosis. Armed with this information, you and your family will have a better idea what to expect in the future and how you can help.

### *Learn how to communicate with healthcare professionals.*

In order to be a better advocate for your loved one, understand and use the terminology that doctors, nurses, discharge planners, therapists and other healthcare professionals use in discussing the case. Be calm but firm in advocating for being a part of the healthcare and support service decision-making.

### *Minimize stress, especially during holidays.*

Holidays can be especially stressful for both caregivers and care recipients. Try to reduce stress, simplify activities, relax, slow the pace and ensure that there is plenty of quiet time to reminisce.

### *Get the extended family involved in caregiving.*

Organize and hold a family meeting involving all decision-makers. Identify and discuss the issues of providing care for the family member in need.

### *Ask for help with household activities.*

Seek help with yard work and other household tasks. Consider asking a friend or neighbor for help.

Hire someone to mow the lawn. Look into delivery services for groceries or drugstore items.

### *Delegate to friends and family.*

Remember, be specific when asking for help from family and friends: “Can Jill come for a couple of hours on Saturdays to stay with Grandma while I do the shopping?” or “Can George mow the lawn every other week now that Dad can’t do it any longer?”

### *Manage your time.*

Keep an appointment book or calendar to schedule your daily activities, including doctors’ visits. Some computer programs or personal devices can help you schedule and manage your time.

### *Seek help that meets your situation.*

Each caregiving situation is unique. For example, if you care for someone who is not living with you and lives a long distance away, you may face special logistical, financial and emotional challenges. Seek out resources that meet your special long distance needs; for example, consider using a geriatric care manager.

# Caregiver Training

You may not be immediately skilled in all of the duties involved in caregiving.

While bathing and feeding someone may seem like simple tasks, there are tips and tricks you can learn to make assisting in the activities of daily living easier.

Safety is also an issue, especially since most care recipients are elderly or disabled in some way.

Some topics to explore in caregiver training might include:

- \* Learning about a particular disease, such as Alzheimer's disease, cancer or HIV/AIDS
- \* How to work with medical professionals and navigate the health care system
- \* Managing activities of daily living, such as bathing, dressing and eating
- \* Preparing your home for safe caregiving
- \* Managing and organizing medication therapy in the home, including recognizing and managing side effects
- \* Operating and managing medical equipment, such as ventilators and oxygen
- \* Specific topic areas, such as pain management or changes in mental status
- \* Coping techniques

## Family caregiver training resources

Caregiving training is available through various sources in the community. Training classes, books, videos and websites can help you with practical skills and strategies for providing care.

The American Red Cross has developed a training program for family caregivers that covers the following topics:

- \* General Caregiving Skills
- \* Home Safety
- \* Positioning and Helping Your Loved One Move
- \* Assisting with Personal Care
- \* Healthy Eating
- \* Caring for the Caregiver
- \* Legal and Financial Issues
- \* Caring for a Loved One with Alzheimer's Disease or Dementia
- \* Caring for a Loved One with HIV/AIDS

Contact your local Red Cross chapter for more information on caregiver training programs.

## The following are additional family caregiving training resources:

The **Center for Caregiver Training** is developing a free online training course for family caregivers. Visit [www.caregiving101.org](http://www.caregiving101.org) for more information.

The **Family Caregiver Alliance** provides an overview of the day-to-day skills family caregivers need to care for the frail elderly or individuals with chronic conditions. For more information, visit its website at [www.caregiver.org](http://www.caregiver.org).

The **Arc of the United States** ([www.thearc.org](http://www.thearc.org)) offers the “Family Handbook on Future Planning,” which focuses on planning for the future needs of children with cognitive, intellectual or developmental disabilities. The Arc also provides an online Family Resource Guide with information available in several states for families raising children with mental retardation and related developmental disabilities.

The **AARP** offers free online seminars on various aspects of family caregiving, including seminars on assisted living facilities and caring for aging parents (go to [www.aarp.org/learntech/family\\_care/](http://www.aarp.org/learntech/family_care/)).

The Chicago-based company **Mather LifeWays** offers a 6-week Internet-based caregiver training course called Powerful Tools for Caregivers (PTC) Online. Visit [www.matherlifeways.com](http://www.matherlifeways.com) for more information.

In addition to these resources, talk to doctors, nurses or social workers about any caregiving tasks that you are uncomfortable performing or find difficult to perform.

## Navigating the Health Care Maze

Patients, family caregivers and even health professionals often do not know what Medicare and health insurance will pay for. Family members and patients are frequently shocked to find that insurance will not pay for many services and items needed at home that are routinely paid for in the hospital.

Unless a care recipient has long-term care insurance (and only a small percentage of Americans do), many home care needs are covered only for an initial, short-term period or are not covered at all. This includes home care aides or attendants.



To help you navigate the complicated health care maze, you should:

 *Know what is covered by insurance, Medicare and Medicaid.*

- \* If your loved one has been hospitalized, insist on speaking with the discharge planner about the care plan before decisions are made. Explore all the options, not just the one the discharge planner recommends.
- \* Find out what the insurance company will approve for your loved one's care, and for how long.
- \* Try to get one person from the insurance or managed care company (a case manager) assigned to your loved one's case and make sure that person fully understands the patient's condition so that the correct home care services and equipment are provided.
- \* Keep detailed records of phone conversations and personal contacts about the case. Write down names, what was said and when. Insurance coverage decisions are often flexible. You may need to document interpretations you have been given by different people.

- \* If there is a home health care nurse or aide assigned by an agency, make sure that person is experienced with your loved one's care and can handle the physical, behavioral and technical aspects of the patient's condition.
- \* Make sure you have been assigned the correct level of home care assistance. Registered nurses, practical nurses and home health aides or personal care assistants have different skills and limitations. There are also different types of agencies, only some of which are certified by Medicare and/or Medicaid.

 *Identify and use all available resources.*

- \* Get to know your local pharmacist. Most are excellent and readily available. Many people requiring care, especially the elderly, take multiple medications. The pharmacist may be able to help identify medication interactions and answer questions about dosing and side effects.
- \* Familiarize yourself with print and Internet resources. Both books and Internet websites provide excellent resources and can put you in touch with other people and

community agencies that can help. There is a vast amount of information on the Internet, so be selective and use credible sources.

- \* Discuss your options with people outside of your network who have experienced your situation.
- \* Have friends and family help with paperwork, such as sorting out bills, reviewing insurance policies, etc. Do not let bills and correspondence pile up.

### *Be assertive about your rights.*

- \* You can say no if the hospital wants to discharge your loved one and you feel you are not prepared to provide the necessary care at home. Be flexible but firm as you negotiate a feasible plan.
- \* Request an aide or home care nurse to come to the

hospital and help you bring your loved one home. This may include riding in the ambulance and setting up the bed or other medical equipment. This service may not be covered by insurance, but it may be worth paying out-of-pocket for professional help to transition your loved one home and get set up.

- \* Make sure your loved one has the proper transportation to and from outpatient visits.
- \* Ask for a re-evaluation of the situation at a specified time (a few weeks or months).

### *Identify how health insurance and other coverage may, and may not, help.*

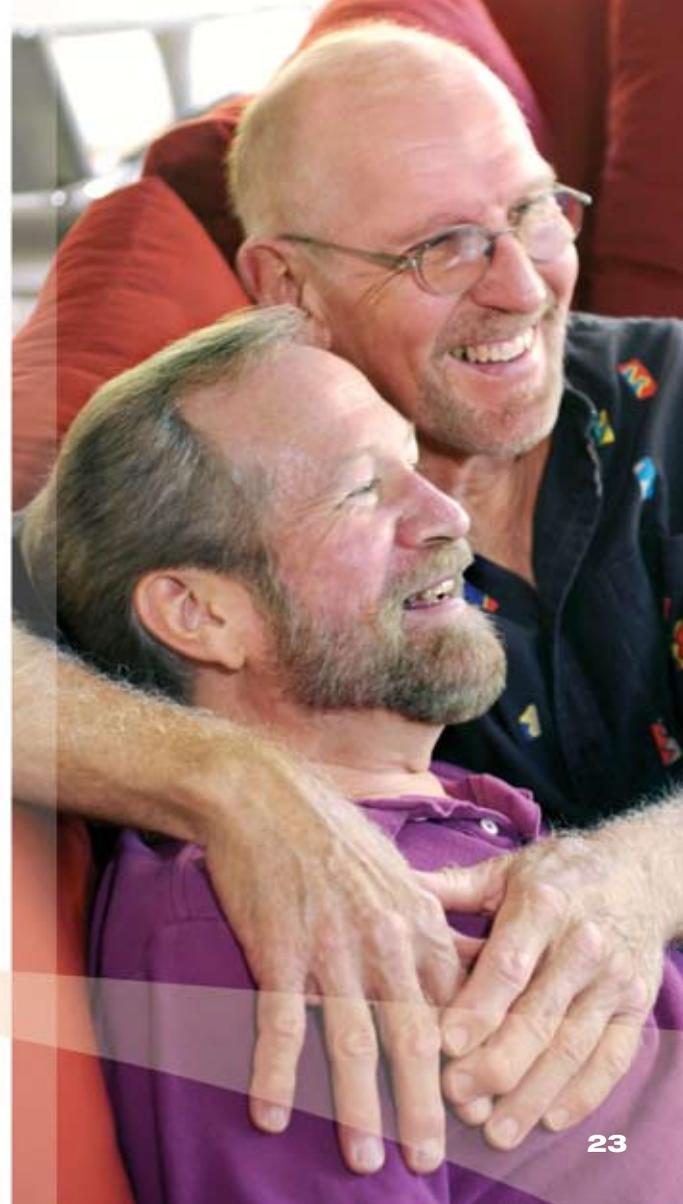
- \* Administering the best possible care (e.g., changing dressings daily and providing other necessities) may be very costly. Such care may not be covered by an insurance policy. You will almost certainly have out-of-pocket expenses for items and services that are not considered “medically necessary.”
- \* Instead of providing greater coverage, having two insurance policies could actually result in less coverage. Each policy may play against the other, delaying or

actually curtailing benefits. Make sure you have a clear agreement as to which payer is “primary.”

- \* A spouse is legally responsible for the partner’s bills, and his/her income is included in determining Medicaid eligibility. Unmarried couples are considered single individuals, making it easier to get Medicaid benefits, which may include home care.
- \* If someone tells you “Medicare [or another insurance] won’t pay for it,” don’t stop there. Check it out yourself through your state Health Insurance Assistance Program, the Medicare Rights Center at (212) 869-3850, online at [www.medicarerights.org](http://www.medicarerights.org) or through another independent source.

- *Contributed by Carol Levine, Director, Families & Health Care Projects, United Hospital Fund*

“**My life partner and I** have been together for 15 years. We are both HIV-positive. We were devastated when I responded to the drug cocktail and he did not. When he developed AIDS, I became his companion, his caregiver and his advocate. I particularly needed assistance with protecting our legal rights and establishing guardianship. A local AIDS service organization and legal aid agency have been very helpful to both of us.”



## Caregiving and Depression

Some family caregivers experience depression, especially those providing intense personal care for many hours a day. About one-third of caregivers say that caregiving is somewhat or very stressful. In addition, women are more likely than men to suffer emotional stress related to caregiving.



## Caregiver Health: Taking Care of Yourself

Caregivers face multiple responsibilities and complex demands of their time, energy and efforts. Many caregivers work full-time outside the home and care for spouses and children as well as frail or ill family members. As a result, caregiving can take a significant physical and psychological toll. It is therefore important for you as a caregiver to take steps to maintain your health and well-being.

While many caregivers report feeling loved, appreciated and needed as a result of their caregiving, many also feel worried, frustrated, sad or depressed and overwhelmed. It is important to build a support system and seek help so you can take care of yourself as well.

### *Take breaks from caregiving.*

Find ways to take breaks from caregiving. Studies have shown that caregiving for prolonged periods of time can adversely affect both your physical and psychological health. It can also negatively affect your employment status and ability to earn a living. Many caregivers report that it is difficult to balance the needs of caring for older parents and other family members with meeting their own personal needs. Seek out respite care to give yourself a break.

Take breaks as often as you can. Take time everyday to engage in a relaxing activity. Read a book, rest, take a walk or exercise, meditate or pray. Just be sure to schedule time for yourself away from your caregiving obligations. While it may seem selfish, taking regular breaks will help you “recharge” and be a better caregiver.

 *Take steps to safeguard your own health and well-being.*

It is important that you attend to your own health. Do not neglect your own health needs at the expense of caring for someone else.

As a caregiver, you should make the following part of your routine:

- \* Go to your primary care physician for regular check-ups, mammograms, prostate exams.
- \* Get a flu shot and pneumonia vaccine. Supplies of the flu vaccine often run short, so be sure to obtain one early in the flu season. Late fall and early winter are ideal.
- \* Take medications and monitor your own health with the diligence and attention you give to those you care for.
- \* Be sure to take time for regular exercise. Even a short walk daily can help you maintain your physical condition, reduce your risk for certain diseases and provide psychological benefit.
- \* Eat a sensible, healthy diet that includes fruits and vegetables.
- \* Consider taking classes and engaging in stress-reduction and coping techniques. Some find yoga, meditation and other relaxation techniques particularly helpful.
- \* Continue to participate in religious or spiritual activities, as well as recreational activities, sports, hobbies or simply spending time with friends.

✓ *Consider joining a support group.*

More than 75% of caregivers report that isolation is their number one source of stress. Look for a local support group for caregivers, where you will be able to share feelings of isolation and frustration. Check the resources in this book and the Internet for “self-help” and support groups. For example, a local chapter of the Alzheimer’s Association (see [www.alz.org](http://www.alz.org)) might hold regular support group meetings for those who care for people with Alzheimer’s. Many people find solace in sharing feelings and seeking emotional support from others who understand first-hand the challenges of caregiving.





**I took in an older sister** with mental

retardation when my mother died suddenly. As her sister, I knew what to expect in terms of her physical and emotional needs. However, as a single parent with a limited income, I quickly realized I was not prepared financially. I found a caseworker through my local Department of Social Services to help me navigate the options for financial assistance.



# The Financial Aspects of Caregiving

Caregiving is a complex and expensive endeavor. Consider the following actions:

## *Review bank and financial arrangements.*

You will need to review issues and perhaps change financial arrangements between yourself as a caregiver and the care recipient.

## *Inquire about the care recipient's medical coverage.*

Chances are your care recipient has some type of medical insurance coverage. It might include private insurance, Veterans' benefits or coverage through Medicare and/or Medicaid. However, be advised that home health care and other long-term care coverage varies widely from one plan to another. In fact, you may be surprised to find that many home health care services and some durable medical equipment (such as wheelchairs or walking aids) are not reimbursed. Don't assume—find out what is covered and plan for what is not.

## *Look into Social Security and pension benefits.*

You may need to determine and make arrangements regarding Social Security and pension payments for the care recipient.

## *Manage family financial planning.*

If you have not done so already, meet with an advisor for planning your family's finances. Seek help to determine the best way to pay for the care for your loved one, now and in the future. You should also consider making arrangements for your own care. For example, you may think about purchasing long-term care insurance for yourself.

## *Plan for care options now, and in the future.*

There are many care options and services available. These include adult day services, supplemental home-based care, occupational and physical therapy, respite care, assisted living and long-term care. All of these care options require financial planning and arrangements.

## The Medicare Modernization Act (MMA) and Medicare Part D

Congress recently passed the Medicare and Modernization Act. This new legislation represents sweeping changes in options for prescription drug coverage for America's senior population.

This voluntary program requires seniors to select a particular plan and sign up. Plans and coverage vary, so it is important that Medicare recipients chose the plan that best fits their needs.

For more information, call 1-800-MEDICARE (800-633-4227) or visit [www.medicare.gov](http://www.medicare.gov) on the Internet.

### The costs of caregiving

Caregiving itself can have financial consequences for the caregiver. For example, you may have to cut back on your work hours, from full-time to part-time, due to caregiving duties. That can have a negative effect on other benefits of employment, such as promotions and 401(K) retirement contributions. One study found that caregivers lose an average \$659,130 over their lifetimes as a result of reductions in their salaries and retirement benefits.

### Caregiver employment

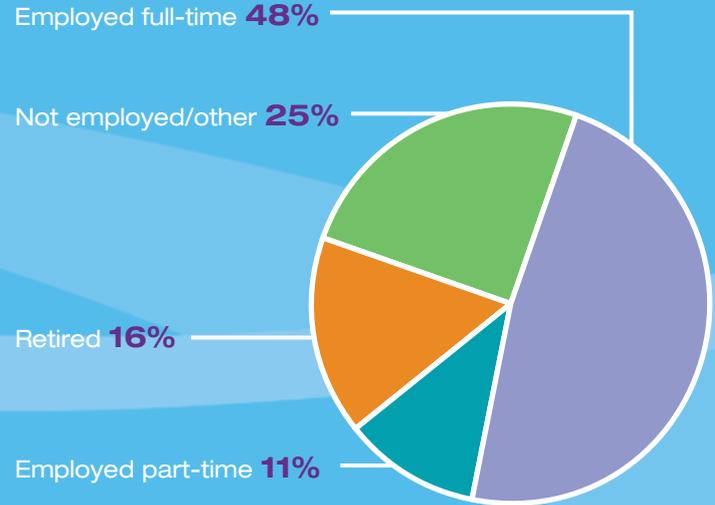
Various studies document that caregivers typically spend between 17 and 24 hours each week caring for the recipient. As many caregivers work outside the home—more than half (48%) are employed full-time—caregiving duties represent a considerable time commitment. Six in 10 employed caregivers report that caregiving forced them to make changes at work, such as going in late, leaving early, taking time off or leaving their jobs altogether.

Employed caregivers have been shown to suffer from more stress-related illnesses and to utilize their company-provided health plans more often. Caregiving has also been shown to have a negative impact at work, leading to decreased productivity, greater absenteeism and loss of work time. Maintaining employment is likely essential to your own financial future, and may also be a source of satisfaction.

The Family and Medical Leave Act (FMLA) allows eligible employees who work for a company with 50 or more employees and are caring for a spouse, parent or child with a serious health condition to take leave from work. For example, those caring for an elderly parent may be eligible to take off 12 work weeks without pay during any 12-month period to care for their parent.

In addition, many companies offer corporate eldercare programs for employees. Your company may also offer other benefits for caregivers, such as telecommuting, flex-time, job sharing, lunchtime caregiving seminars, an information and referral program to local resources, on-site support groups or a geriatric care management program. Check with your company's Employee Assistance Program or Human Resources department to learn about available programs.

## Employment Status of Caregivers



## Caregivers on average

spend four and a half years of their lives delivering care.

# Legal Issues of Caregiving

Caregiving involves various legal issues that can seem confusing and complicated. This is especially true if the care recipient is impaired or facing end-of-life issues. You will likely need to seek out assistance from an attorney or a legal aid group specializing in elder law.

Many caregiving organizations offer educational seminars and information online about the legal aspects of caregiving. Some of the actions you might consider include the following:

## *Find an attorney.*

Ask family, friends and others in similar situations for referrals or recommendations. Many caregiving organizations maintain legal referral lists. Look for an attorney who specializes in elder law.

## *Pursue legal documents regarding the health of the care recipient.*

There are a number of legal instruments designed to establish the wishes of the care recipient. Through a health care proxy and medical power of attorney, an agent is appointed to make medical decisions for someone who can no longer make decisions. A living will states a person's wishes regarding his or her health care, particularly those regarding end-of-life decisions. A HIPAA release authorizes an agent to have access to a person's private medical information.

## ✓ *Consider a power of attorney and other related legal documents.*

It's best to prepare a power of attorney and/or a living trust as early as possible, as the care recipient must have the mental capacity to understand the document.

## ✓ *Look into estate planning.*

Estate planning allows the care recipient to determine how their assets and property should be distributed in the event of their death.

### **Planning for the future**

Now is the time to look to your own future. Initiate a conversation with your family about your wishes if you should one day require care. Issues to explore include establishing a health care directive regarding your medical wishes, housing and long-term care preferences and naming a caregiver. Consider long-term care insurance as a financial safeguard.

*- Legal and financial information contributed by Robert M. Freedman, Esq., Freedman Fish & Grimaldi LLP, New York, NY*



November is  
National Family  
Caregivers Month.

Look for special activities and events in your area throughout the month of November each year.

## Conclusion

Your caregiving journey may be rewarding—and difficult. Remember, you are not alone as a family caregiver and help is out there.

Some things to consider:

- \* Take charge of your life, and don't let your loved one's illness or disability always take center stage.
- \* Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- \* Watch out for signs of depression, and don't delay in getting professional help when you need it.
- \* When people offer to help, accept the offer and suggest specific things that they can do.

- \* Educate yourself about your loved one's condition. Information is empowering.
- \* There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- \* Trust your instincts. Most of the time, they'll lead you in the right direction.
- \* Grieve for your losses, and then allow yourself to dream new dreams.
- \* Stand up for your rights as a caregiver and a citizen.
- \* Seek support from other caregivers. There is great strength in knowing you are not alone.

- *Contributed by the National Family Caregivers Association.*

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# Caregiver Resource Guide *Where to turn for help*

## Caregiver Information

### *National Alliance for Caregiving*

4720 Montgomery Lane, 5th Floor

Bethesda, MD 20814

WEB: [www.caregiving.org](http://www.caregiving.org)

EMAIL: [info@caregiving.org](mailto:info@caregiving.org)

### *Family Caregiver Alliance (FCA)*

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

TOLL-FREE: 1-800-445-8106

WEB: [www.caregiver.org](http://www.caregiver.org)

EMAIL: [info@caregiver.org](mailto:info@caregiver.org)

### *National Family Caregivers*

#### *Association (NFCA)*

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895-3944

TOLL-FREE: 1-800-896-3650

PHONE: 1-301-942-6430

FAX: 1-301-942-2302

WEB: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

EMAIL: [info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)

### *Today's Caregiver Magazine*

WEB: [www.caregiver.com](http://www.caregiver.com)

### *Family Caregiving Information*

WEB: [www.familycaregiving101.org](http://www.familycaregiving101.org)

### *Children of Aging Parents (CAPS)*

P.O. Box 167

Richboro, PA 18954

TOLL-FREE: 1-800-227-7294

WEB: [www.caps4caregivers.org](http://www.caps4caregivers.org)

EMAIL: [info@caps4caregivers.org](mailto:info@caps4caregivers.org)

### *Well Spouse Association*

63 West Main Street, Suite H

Freehold, NJ 07728

TOLL-FREE: 1-800-838-0879

WEB: [www.wellspouse.org](http://www.wellspouse.org)

EMAIL: [info@wellspouse.org](mailto:info@wellspouse.org)

## Housing

### *American Association of Homes and Services for the Aging (AAHSA)*

WEB: [www.aahsa.org/consumer\\_info/default.asp](http://www.aahsa.org/consumer_info/default.asp)

### *Homecare Online—National Association for Home Care and Hospice*

WEB: [www.nahc.org/Consumer/coninfo.html](http://www.nahc.org/Consumer/coninfo.html)

### *Assisted Living Federation of America (ALFA)*

WEB: [www.alfa.org](http://www.alfa.org)

## Aging Resources

### *AARP*

601 E Street, NW  
Washington, DC 20049  
TOLL-FREE: 1-888-OUR-AARP  
(1-888-687-2277)  
WEB: [www.aarp.org](http://www.aarp.org)

### *National Institute on Aging Information Center*

P.O. Box 8057  
Gaithersburg, MD 20898-8057  
TOLL-FREE: 1-800-222-2225  
TOLL-FREE TTY: 1-800-222-4225  
WEB: [www.nia.nih.gov](http://www.nia.nih.gov)

### *The National Council on the Aging (Headquarters)*

300 D Street, SW, Suite 801  
Washington, D.C. 20024  
PHONE: 1-202-479-1200  
FAX: 1-202-479-0735  
TDD: 1-202-479-6674  
WEB: [www.ncoa.org](http://www.ncoa.org)  
EMAIL: [info@ncoa.org](mailto:info@ncoa.org)

### *Administration on Aging (US Department of Health & Human Services)*

PHONE: 1-202-619-0724  
WEB: [www.aoa.gov](http://www.aoa.gov)

*Eldercare Locator (to find services for an older person or a family caregiver in his or her locality):*

PHONE: 1-800-677-1116

WEB: [www.eldercare.gov](http://www.eldercare.gov)

### *Medicare*

PHONE: 1-800-Medicare

WEB: [www.medicare.gov](http://www.medicare.gov)

### *Benefits Check Up*

WEB: [www.benefitscheckup.org](http://www.benefitscheckup.org)

### *National Association of Professional Geriatric Care Managers*

1604 N. Country Club Road

Tucson, AZ 85716-3102

PHONE: 1-520-881-8008

WEB: [www.caremanager.org](http://www.caremanager.org)

## **Mental Health**

### *National Alliance for the Mentally Ill (NAMI)*

Colonial Place Three

2107 Wilson Blvd., Suite 300

Arlington, VA 22201-3042

PHONE: 1-703-524-7600

TDD: 1-703-516-7227

TOLL-FREE INFORMATION HELPLINE:

1-800-950-NAMI (6264)

WEB: [www.nami.org](http://www.nami.org)

### *National Mental Health Association*

2001 N. Beauregard Street, 12th Floor

Alexandria, VA 22311

PHONE: 1-703-684-7722

TOLL-FREE: 1-800-969-NMHA (6642)

TTY: 1-800-433-5959

WEB: [www.nmha.org](http://www.nmha.org)

## **Other**

### *Alzheimer's Association*

225 N. Michigan Ave., Fl. 17

Chicago, IL 60601-7633

TOLL FREE: 1-800-272-3900

LOCAL: 1-312-335-8700

FAX: 1-312-335-1110

WEB: [www.alz.org](http://www.alz.org)

EMAIL: [info@alz.org](mailto:info@alz.org)

## **Respite Care**

### *National Adult Day*

#### *Services Association, Inc.*

2519 Connecticut Ave., NW  
Washington, DC 20008  
TOLL-FREE: 1-800-558-5301  
PHONE: 1-202-508-1205  
FAX: 1-202-783-2255  
WEB: [www.nadsa.org](http://www.nadsa.org)  
EMAIL: [info@nadsa.org](mailto:info@nadsa.org)

### *National Respite Locator Service*

WEB: [www.respitelocator.org](http://www.respitelocator.org)

### *ARCH National Respite Network*

Chapel Hill Training-Outreach Project, Inc.  
800 Eastowne Dr. Suite 105  
Chapel Hill, NC 27514  
WEB: [www.archrespite.org](http://www.archrespite.org)  
PHONE: 1-919-490-5577  
FAX: 1-919-490-4905  
TDD: 1-919-490-5577

### *Eldercare Locator Search*

*(For respite care and other services)*

INFORMATION LINE: 1-800-677-1116  
WEB: [www.eldercare.gov/Eldercare/Public/  
Home.asp](http://www.eldercare.gov/Eldercare/Public/Home.asp)

## **Hospice**

### *Hospice Foundation of America*

1621 Connecticut Ave., NW, Suite 300  
Washington, DC 20009  
PHONE: 1-800-854-3402  
WEB: [www.hospicefoundation.org](http://www.hospicefoundation.org)  
EMAIL: [info@hospicefoundation.org](mailto:info@hospicefoundation.org)

### *Hospice Net – Information for Caregivers and Hospice*

WEB: [www.hospicenet.org/html/  
caregivers.html](http://www.hospicenet.org/html/caregivers.html)

### *National Hospice & Palliative Care Organization (NHPCO)*

1700 Diagonal Road, Suite 625  
Alexandria, VA 22314  
WEB: [www.nhpc.org](http://www.nhpc.org)  
NHPCO HELPLINE: 1-800-658-8898

## Legal and Financial Resources

### *Social Security Administration*

PHONE: 1-800-772-1213

WEB: [www.ssa.gov](http://www.ssa.gov)

### *Centers for Medicare and Medicaid Services*

TOLL-FREE: 1-877-267-2323

TOLL-FREE TTY: 1-866-226-1819

WEB: [www.cms.hhs.gov](http://www.cms.hhs.gov)

### *American Bar Association (ABA) Commission on Law and Aging*

740 15th Street, NW, 8th Floor

Washington, DC 20005

PHONE: 1-202-662-8690

TOLL-FREE: 1-800-285-2221

WEB: [www.abanet.org/aging](http://www.abanet.org/aging)

### *National Academy of Elder Law Attorneys (NAELA)*

1604 North Country Club Road

Tucson, AZ 85716

PHONE: 1-520-881-4005

FAX: 520-325-7925

WEB: [www.naela.org](http://www.naela.org)

### *Financial Planning Association*

WEB: [www.fpanet.org/public/index.cfm](http://www.fpanet.org/public/index.cfm)

### *Women's Institute for a Secure Retirement (WISER)*

WEB: [www.wiser.heinz.org](http://www.wiser.heinz.org)





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The National Family Caregiver Support Program. U.S. Administration on Aging, Department of Health and Human Services.

National Family Caregiver Support Program SNAPSHOT. U.S. Administration on Aging, Department of Health and Human Services. 08/27/03.

What We Do Makes a Difference Fact Sheet: Family Caregiving. U.S. Administration on Aging, Department of Health and Human Services.



## NATIONAL ALLIANCE for CAREGIVING

The National Alliance for Caregiving is a nonprofit coalition of more than 40 national organizations that focuses on issues of family caregiving across the lifespan. Established in 1996 by founding members AARP, the American Society on Aging, the National Association of Area Agencies on Aging, The National Council on the Aging and the US Department of Veterans Affairs, the Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues.

Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

-Gail Gibson Hunt, President and CEO

**CARE** for the  
**FAMILY**  
**CAREGIVER:**  
A Place to Start



## HIP HEALTH PLAN OF NEW YORK, Integrative Wellness Department

For over 50 years, HIP has built its reputation on an ability to anticipate change and to respond in innovative ways. Long before preventive care was widely accepted as a core medical strategy, HIP was pioneering services in that arena. In the decades since, it has continually adapted to the evolving health care landscape to improve the health and well-being of members.

Through the Integrative Wellness department, HIP serves its members by promoting overall wellness—body, mind and spirit. By emphasizing self-care and lifestyle modification, our activities encourage HIP members to become more aware of the connection between the mind and the body, and to appreciate the growing scientific evidence that each of us has the capacity to control stress and harness the healing power within.

At HIP we recognize that few jobs are as demanding as being an unpaid family caregiver. Research findings show that the burdens of caring for a chronically ill or disabled relative or friend put the caregiver at risk for emotional and physical problems, particularly depression. To heighten awareness of the risk factors and provide information and resources, Integrative Wellness initiated Care for the Caregiver, a program to help caregivers stay healthy and not become care recipients themselves. Visit [hipusa.com](http://hipusa.com)® and click on Integrative Wellness for more information about our Care for the Caregiver initiative, including links to city, state and national organizations.

-Anthony L. Watson, Chairman and CEO

## Acknowledgements

Dear Caregiver:

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We also want to thank you—for caring for a loved one, family member, a partner or a friend. None of us is alone in this caregiving journey. It is a constantly unfolding experience, and we trust you have now found a place to start and together we move forward, SHARING the CARING.

We wish you well on your caregiving journey. Together we care and share the caring.

Sincerely,

Gregory L. Johnson  
CARE for the CAREGIVER PROGRAM  
HIP HEALTH PLAN OF NEW YORK

Gail Gibson Hunt  
Founder and CEO  
NATIONAL ALLIANCE  
for CAREGIVING