



# CARE FOR THE FAMILY CAREGIVER: A Place to Start

PREPARED BY:





## NATIONAL ALLIANCE FOR CAREGIVING

For twenty years, I have been proud to lead the National Alliance for Caregiving and work to elevate family caregivers in the United States and across the globe. Established in 1996, the Alliance is a non-profit coalition of national organizations. Together we create new research, identify innovations and best practices, and advocate on behalf of America's 43.5 million family caregivers.

We continue to lead research through our Caregiving in the U.S. reports, issued every five years with AARP — the most recent is the 2015 version. The Alliance conducts special research on the financial impact of caring, Alzheimer's and dementia caregiving, caregivers of loved ones with mental illness, and the challenges facing special populations of caregivers, including rural caregivers, caregivers of Veterans, and children caring for parents or grandparents.

Our community's work to increase public awareness of the issues facing family caregivers and the changes in the field since the mid-1990s has been astounding. The federal government has begun to provide assistance to families caring for a loved one, including the National Family Caregiver Support Program through the Administration on Community Living and the Department of Veterans Affairs Caregiver Support Program.

Still, there is much work to be done. EmblemHealth's Care for the Family Caregiver initiative has been one of the initiatives that addresses the whole family caregiver and it provides a proven model for others to emulate. We hope you will find this guidebook useful and join the growing movement of family caregivers seeking better support and wellness. To learn more about our work, please visit [www.caregiving.org](http://www.caregiving.org).

— Gail Gibson Hunt, President and CEO

## EMBLEMHEALTH

We are proud of our work supporting family caregivers. We recognize that few jobs are as demanding as caring for a chronically ill or disabled loved one. Research shows that the challenge of being a family caregiver increases the risk of physical and emotional problems, particularly depression which is why our health plan has a long tradition of service for these “silent supporters” who play a vital role in caring for loved ones.

Our updated and expanded third edition of Care for the Family Caregiver: A Place to Start is available on the web at [emblemhealth.com/careforthefamilycaregiver](https://emblemhealth.com/careforthefamilycaregiver).

As a founding member of the New York City Family Caregiver Coalition, and the New York City Partnership for Family Caregiving Corps, EmblemHealth is committed to helping caregivers access information and support. We want family caregivers to know they are not alone.

It is our hope that these resources will provide peace of mind and comfort to families in our community, across the country and across the world.

— Karen Ignagni, President and CEO



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# INTRODUCTION

## WELCOME TO CARE FOR THE FAMILY CAREGIVER: A PLACE TO START.

Let us begin by saying **“thank you”** for all that you do. We know you might feel overwhelmed about your role as caregiver, so we are offering resources and support in this booklet to show you that you are not alone.

This booklet serves family caregivers, meaning anyone who cares for relatives or loved ones. The efforts might be for a member of the caregiver’s *family of origin* or his or her *family of choice*, such as a 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.



Know that as a caregiver, you are not alone. In fact, experts estimate that nearly 43.5 million people in the United States are caregivers to adult friends or family members.

## THE CONTEXT OF CAREGIVING

### WHAT IS A CAREGIVER?

Society, advocacy groups, the health care industry and the government all have definitions for “family caregiver.” America is the only place where this term is used. Elsewhere these people are called **carers**. We think the emphasis on family is important, which is why we have prepared this booklet.

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 (non-paid), family caregivers.

To understand the importance of a caregiver, think of health care as a three-legged stool. Family caregivers serve as one leg of the stool; professional caregivers (doctors, nurses, etc.) act as another; and the care recipient is the third leg. Without all three legs, health care cannot be as effective as it needs to be.





## **FACING THE CALL TO CAREGIVING**

We want to emphasize that you as a family caregiver are not alone. Although you may feel isolated, you are part of a larger community. Nearly 43.5 million Americans provide unpaid care for an adult family member. That's nearly one in every three people.

If you look around, you might discover:

- Your coworker cares for an elderly parent at home.
- A friend is 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 for a developmentally disabled child while handling congregational responsibilities.

The care doctors, nurses and other health professionals provide is essential, but so is the care you give at home. Each caregiver situation is unique, yet all share universal experiences that encompass physical, emotional and spiritual — as well as economic and legal — concerns.

## **WHAT YOU WILL FIND INSIDE THIS BOOKLET**

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



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.

## 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 information about many important and universal elements 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 will be most helpful to you. You may want to start a file, create a bookmark list of Internet sites or designate a special place in your home for caregiving resources, including this one.

You may discover a topic in this booklet that you have not yet considered, such as 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 IMPORTANT TO ASK FOR HELP. THAT'S THE SMART APPROACH.

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.

Caregiving presents considerable challenges — physical, emotional and economic. There is no reason to struggle alone. If you take 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 as if 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. This also can 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 one place to start. Another is our website: [www.emblemhealth.com/careforthefamilycaregiver](http://www.emblemhealth.com/careforthefamilycaregiver).

## 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 own. 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.





## **MINDFUL LOVING COMPASSION**

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University Langone Medical  
Center, offers the following  
suggestions for ways  
you can find joy in quiet  
times with your loved one.

### **FAMILY CAREGIVER STORIES**

#### **Caring for a spouse: Nancy's journey**

Nancy 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 found her days filled with endless tasks and appointments, leaving 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.

#### **Mindful Loving Compassion**

When we are overwhelmed with tasks, particularly the feelings that arise when caring for another, it is not unusual to feel resentful, and then guilty because we feel resentful. We can sometimes lose touch with feeling empathetic for the person for whom we are caring. One of the ways in which we can re-connect with our true sense of empathy is with a mindfulness activity called "Loving Compassion." With repeated attempts, we can learn

to practice Mindful Loving Compassion in the presence of another. This type of practice can be especially helpful if we must sit next to our loved one while they are resting or sleeping.

Resting comfortably in a chair, close your eyes, breathing softly in and out through your nose, and feel the breath in and around your nostrils. Imagine in your mind's eye an image of yourself exactly as you are, i.e., tired, exhausted, depleted. Then imagine that part of you that can assume a wise, caring state of being and through that voice say:

*May I be safe,*

*May I be happy, or at ease,*

*May I be healthy,*

*May I be loved.*

Then imagine the person whom you are caring for, and offer the same:

*May you be safe,*

*May you be happy, or at ease,*

*May you be healthy,*

*May you be loved.*

Follow this by including others whom you may care for such as your children, and then go back to yourself. Try to go around the circle two or three times every day.

## **Remembering Our Story**

Sitting with your loved one, recall earlier times in your relationship. Go back to when you first met, what attracted you to one another, what invited you to stay, what kept you going when times were challenging, and what you found particularly restorative, or gave you hope that your story was a story that would continue.

Write the narrative down as you talk about your story together. You may also wish to consider offering a recorder to your loved one if he or she is not able to write. Interweave the story, as it is important that the story contain elements from both of you. Then share the completed story with each other, as well as with loved ones and friends.

## **Eye Gazing**

If talking is not possible, and even when talking is possible, try just looking comfortably into each other's eyes for a few moments at a time. Reconnect with one another, see each other as you are, and remember a time when you felt safe and secure. Remember that not everyone will feel comfortable sustaining a gaze such as this for long. If that is the case, allow your loved one, or you, to shift the gaze and look away, and then after a few moments, return to looking comfortably into each other's eyes.

## **Holding One Another – Touch Can Be Restorative**

Sometimes when we are caring for our loved one, the individual who is in bed can feel uncomfortable or infantilized, particularly when they have spent much of their lives caring for us. If you can safely and comfortably lie on the bed next to your loved one, consider the comfort and restoration that comes with touch. Assume the spooning position with you inside of the spoon so that the one who is being cared for can rest a hand comfortably on your stomach. Maintain the position until you both relax. Perhaps you will even fall asleep.

## Lives interrupted: A family changes forever

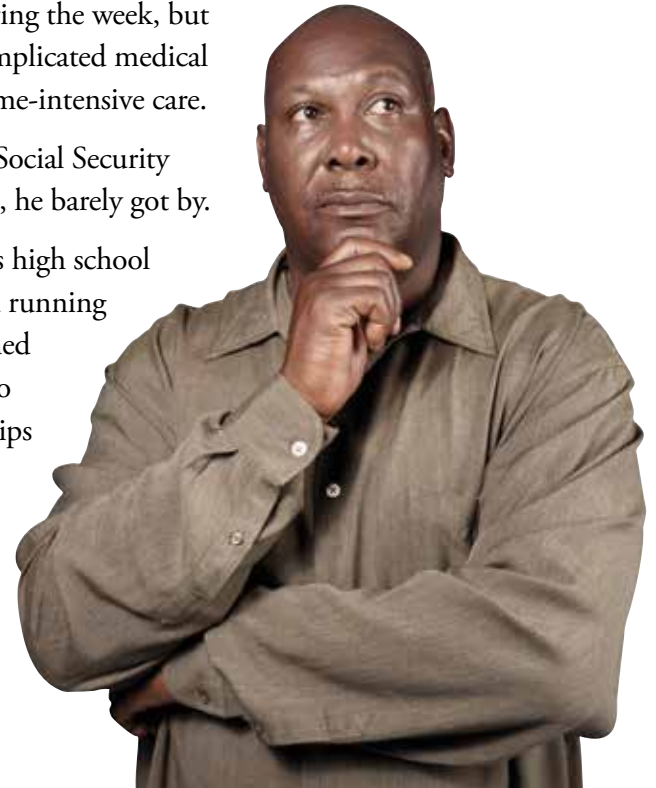
In an instant, Nick's family changed forever when a car accident claimed the life of his wife and left his 15-year-old son with a serious spinal cord injury. He found himself suddenly responsible for everything from housework to looking after his two daughters who missed their mother terribly as he became one of the millions of caregivers in the U.S. who provide care for a child with special needs.

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. Caregivers of children with special needs provide the most time-intensive care.

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. 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.

***Your support group can help you learn about grants that help pay for someone to care for your loved one. It also is important to line up family members and friends to relieve you on a regular basis.***



### **Cecile and Agnes: Facing the golden years together**

At 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, although their situation is becoming more common. In recent years, a larger percentage of caregivers have reported that either Alzheimer's or dementia is the primary reason their loved ones require care.

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 and was able to sustain this positive outlook thanks to the help she received from a support group.

For more information, visit [caringkindnyc.org](http://caringkindnyc.org).





## **Roxie grows up too soon: When a child becomes the adult**

Before her mother developed debilitating Multiple Sclerosis (MS), Roxie was a vivacious, happy teenager with dreams of landing a college scholarship and becoming a physician. Her mom had been diagnosed with MS when Roxie was 10 and her younger siblings were toddlers. Although her mother initially responded to treatment, by Roxie's sophomore year of high school, the medication failed and her mother's MS progressed. While her friends prepared for junior prom, Roxie found herself caring for her mother and two rambunctious younger brothers.

Fearing being placed in a foster home or getting separated from her brothers, Roxie kept her struggle quiet, telling no one what was happening at home. After school became a marathon of tasks — grocery shopping, preparing meals, helping her mother bathe, laundry and keeping their modest home clean. There was little time for homework, and Roxie's grades dropped. Normally an A student in science, her biology teacher, Mr. Grant, took notice. He earned Roxie's trust and she finally confided in him about her situation at home.

With the help of her guidance counselor and a social services caseworker, Roxie received the assistance she needed from a combination of home health care aides and a family member who agreed to move closer. Roxie returned her focus to schoolwork, although she worries what will happen to her younger brothers if she moves away for college, and she is looking at universities close to home.

Roxie is not alone. A 2014 study by the American Academy of Pediatrics found that more than 1.3 million children care for a family member who suffers from a physical or mental illness or substance abuse problems, spending about 2.5 hours during the week and four hours on the weekend caring for a loved one. The median age of child caregivers was 12.

**For more information about children as caregivers, visit the National Alliance for Caregiving at [www.caregiving.org](http://www.caregiving.org) and [caregiver.com/articles/children/children\\_as\\_caregivers.htm](http://caregiver.com/articles/children/children_as_caregivers.htm). Also check out the blog post “Who Is a Caregiver at the Age of 20? Advice From a Young Caregiver” by Samantha Whitmarsh, who cares for her mother as she battles cancer — [www.caregiver.org](http://www.caregiver.org).**





**The typical American caregiver is a woman who works and spends about 24 hours a week providing care.**

*No matter what your caregiving situation is, it's important that you build support. Ask a friend to stay with your loved one so you can get out for a bit. Outside and online support groups may be found through Family Caregiver Alliance — [www.caregiver.org](http://www.caregiver.org).*

## THE FACE OF THE FAMILY CAREGIVER

Caregivers are all around us. Nearly 43.5 million Americans serve as informal caregivers to a child with special needs or an adult who lives in the community and requires help. Spouses, adult children, other family members, partners, friends and neighbors all serve as unpaid, informal caregivers. Most caregivers (86%) are related to the care recipient, 36% care for a parent.

Studies have shown that caregivers are all ages and come from all walks of life, although in recent years the age of both caregivers and care recipients has increased. The average age of a caregiver is 48. More than half of all caregivers are between 18 and 49 years old.

The majority of family caregivers are women who devote about 24 hours a week to caring for their loved ones — the equivalent of a second, part-time job. The care of a family member, in the absence of a spouse, often falls on the shoulders of a daughter or daughter-in-law. Many women spend a large percentage of their adult lives caring for children and adult family members, in addition to working outside of the home.

Some differences have been reported in caregiving among different ethnic groups. African-American caregivers were on average older than their counterparts, and more likely to be single or never married. Forty-one percent of African-American caregivers were more likely to provide help with more than three activities of daily living — getting in and out of bed, dressing, feeding, managing incontinence or getting to and from the toilet — than white caregivers (28%), or Asian-Americans (23%). Experts have noted that cultural and ethnic differences may influence expectations on family caregivers.



### Faces of Family Caregiving

Seniors caring for seniors

Caring for parents or grandparents

Seniors caring for grandchildren (kinship)

Caring for one with a chronic condition

Long distance caring

Caring for end of life in the middle of life

Caring in the LGBT community

Caring for Veterans

## THE EXPANDING ROLE OF FAMILY CAREGIVERS

Six in 10 caregivers of someone older than 50 assist with medical/nursing tasks. Recent research has revealed that in addition to activities of daily living, family caregivers are increasingly performing tasks that nurses typically perform. Known as “medical/nursing tasks,” these skilled activities include, but are not limited to:

- Managing medications
- Preparing and administering intravenous feedings
- Giving injections
- Helping with assistive devices for mobility
- Preparing food for special diets
- Providing wound or ostomy care
- Using meters and monitors (glucometers, blood pressure monitors, oxygen saturation monitors)
- Using incontinence supplies
- Operating medical equipment (lifts, home dialysis equipment, suctioning equipment)

***“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.”***

## **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 most long-term care at home in the United States: 58% of care recipients 50 or older live in their own home and 20% live with their caregiver. Only 5% live in a nursing home or assisted living facility.

Caregiving by 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 more than \$450 billion each year.

***“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.”***



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.

## WHO ARE CARE RECIPIENTS?

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. Those who care for children with special needs also are recognized as family caregivers as their responsibilities are unique and more time-intensive than general parenting.

“Grandparent caregivers” raising grandchildren may 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. People may require temporary, long-term or indefinite care. When asked, caregivers often simply cite “old age” as the primary reason a recipient requires 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
- Cancer
- Mental health and psychiatric disorders; Attention Deficit Disorder (ADD or ADHD)
- Cardiovascular diseases such as stroke or heart attack
- Injury, such as traumatic brain or spinal cord injury
- Developmental disability, mental retardation, or autism
- Diseases associated with ongoing disability, such as diabetes, severe arthritis, HIV/AIDS.



**Those who care for children with special needs also are recognized as family caregivers as their responsibilities are unique and more time-intensive than general parenting**



## THE GRAYING OF AMERICA

People aged 65 and older continue to be among the fastest growing segment of the U.S. population, now making up 13 percent of the population. This population is expected to grow steadily for many reasons, among them declining fertility, the aging “Baby Boom” generation and longevity. Americans are living longer. By the time the Baby Boomers begin to reach 85 in 2031, 21 million Americans will be 65 or older. Caregivers, and care recipients, will likewise become older, resulting in greater demands for resources and assistance.

*“What we are seeing now just may be the perfect storm of demographics, media attention, technological and health care advances, and advocacy efforts to improve the quality of life for family caregivers and for whom they care,” said Kathleen Kelly, MPA, executive director, Family Caregiver Alliance/National Center on Caregiving. “There are big issues yet to tackle, but the growing awareness of the issues along with the victories made over the past five years, progress can and must be made to better support family caregivers.”*

## TRENDS IN CAREGIVING

In a November 2015 report, “Not Your Grandmother’s Caregiving,” the Family Caregiver Alliance looked at trends in the field and noted a significant increase in attention given to issues of unpaid family caregiving over the last five years. One of the reasons for the interest is that movies and memoirs have put a face on caregiving by recounting personal experiences.



The report considered four factors, the first being the societal shift as populations across all developed countries age. Those over age 80 are the fastest growing percentage of this trend. “This is shifting the way communities plan from housing to transportation, how resources are reallocated within health care, and how economists view future economic growth and demand for certain products and services to serve an older age segment,” the report says.

Second, advances in research and treatment for many diseases have lengthened life spans. While basic research at the federal level has been cut, research for dementia and other chronic conditions has seen increases. Researchers also “are collaborating to develop databases that serve multiple research purposes and extend internationally so the pace of discoveries can be accelerated — all good changes,” the report says. “However, homes have become more medical as care has shifted from health facilities to homes, with caregivers typically providing the majority of complex care required for advanced illnesses.”

Third, technology changes allow everyone to search for health information, connect with other patients and families with similar conditions, monitor health conditions or make caregiving easier at the home. “While no ‘killer apps’ have appeared to capture large market shares quite yet, it is hard to miss the implications of over a million downloads for an app found in the Kaiser system that gives patients and families instant access to medical records, information, pharmacy services, and to their doctors,” the report says. Other technological advances are also now widely available, including emergency response devices, electronic calendars and devices that send medical information to health care providers, such as blood sugar levels or blood pressure.

In addition, advocates are supporting policies that will regulate changes within the Centers for Medicare and Medicaid Services, paid family leave, state plans for family caregivers and ensure that all discharges from a hospital require adequate communication and training for both the patient and their caregiver(s). In the works is the first Institute of Medicine report on family caregiving. “While not an orchestrated advocacy movement, it is a persistent push to ensure that families are recognized for their roles as caregivers and for them to receive the support that they deserve,” the report says. See the Caregiver Resource Guide at the end of this booklet for a comprehensive list of resources available to family caregivers.

## ADDITIONAL OPTIONS IN CARE

### RESPITE CARE

Respite for family caregivers also has gained attention. 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 paid home health care aide or provider. 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. 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.



### PALLIATIVE CARE

Palliative care is a multidisciplinary approach to specialized medical care for people with serious illnesses. A team of doctors, nurses and other health care professionals work together to provide relief from the symptoms of pain and the physical and mental stress of a serious illness.

### HOSPICE CARE

Hospice care focuses on the emotional and spiritual needs of chronically ill, terminally ill or seriously ill patients. The care can be provided in hospitals or nursing homes as well as at home.

## HELPFUL TIPS FOR FAMILY CAREGIVERS: A PLACE TO START

Caregiving can require 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. 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 AARP. (Go to [www.aarp.org](http://www.aarp.org) and search Home Safety Caregiving Checklist.)

### **Get caregiver training**

Seek educational resources in caregiving. (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 or hospital admissions.

Most care recipients take at least one prescription drug. It's important to keep a list of all medications, including over-the-counter drugs, the care recipient is taking. Be sure to also record the dosage or strength, such as 10 mg; for what condition the drug is taken; and how often it is taken, such as twice a day. A drug regimen may change often, so be sure to make regular updates. Pharmacists in particular are valuable resources for medication information.

If your loved one has access to a personal health record (PHR), use it to record symptoms, doctor visits, medications and other important health information.

☑ **Educate yourself**

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.

☑ **Ask for help**

Seek help with yard work and other household tasks. Consider asking a friend or neighbor. Hire someone to mow the lawn. Look into delivery services for groceries or drugstore items. Find ways to free yourself from some responsibilities. And when asking for help, be specific. “Could you stay with Mom for three hours on Friday afternoon while I go to the dentist?” is better than “I need help with Mom.”

☑ **Learn how to communicate with health care professionals**

To better advocate for your loved one, understand the terminology used by doctors, nurses and the other health care professionals. If something you hear or read is unclear, don't be afraid to ask questions.

If you feel the health care team doesn't fully understand your loved one's needs and concerns, speak up. Good two-way communication between patients and providers is critical. You can play a valuable role in helping with this.

☑ **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. Consider using an online calendar you can share with other family members on the Internet, such as Google Calendar.

☑ **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.

☑ **Seek help that meets your situation**

Each caregiving situation is unique. 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 resources that meet your special long distance needs; for example, consider using a geriatric care manager.

☑ **Get the extended family involved in caregiving**

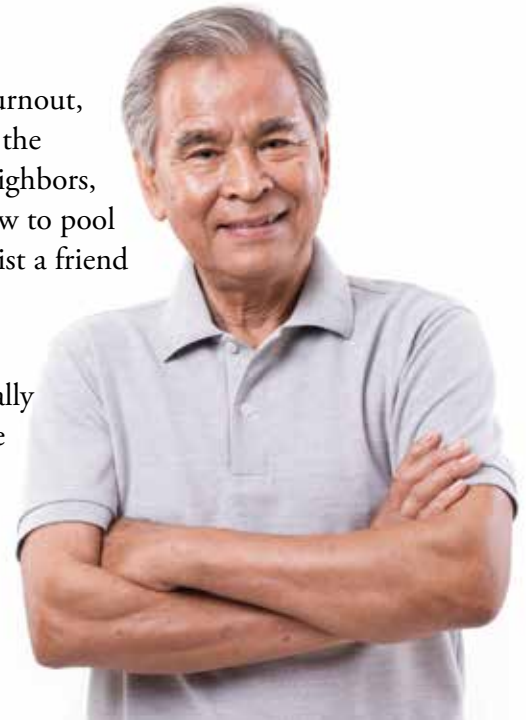
Hold a family meeting involving all decision makers. Identify and discuss the issues of providing care for the family member in need. Come up with a plan to share responsibilities and to keep everyone updated regularly.

## SHARE THE CARE™

### **An Evidence Informed Grassroots Model for Group Caregiving**

No matter if you're a frightened first-time caregiver or a veteran caregiver facing burnout, there is no need to take on the overwhelming task of caregiving alone. Since 1995 the award winning Share The Care™ model has been empowering friends, relatives, neighbors, and co-workers across the U.S. and other countries with a step-by-step plan on how to pool their time, efforts and resources to create and maintain a “caregiving family” to assist a friend or loved one facing a health, aging or medical crisis.

The model was born when 12 women (who didn't know each other) came together and stayed together for nearly four years to care for a mutual friend who was terminally ill. Over time they developed ways of working and rotating responsibilities so no one person was overwhelmed. Later their systems were documented into a book for others to replicate.



Recent research confirms that Share The Care™ can make a difference for everyone involved regardless of the challenge or circumstance. Share The Care™ recipients, families and caregivers alike, confirm that they have experienced solace, support and even joy in the midst of difficult and sometimes, tragic life circumstances.

Share The Care™ offers friends and family the best answer to the most frequently asked question “What Can I do to Help?” by teaching them how to:

- Identify friends, relatives, neighbors, business associates, and acquaintances to invite into their caregiving family.
- Introduce the group to the Share The Care™ system, which allows individuals to choose jobs they feel comfortable doing.
- Discover hidden talents within the group, make the most of their resources, cope with group issues and stay together even in the face of adversity.
- Deal with their own emotional issues while helping someone who is facing their own fears.

Turn caregiving into a meaningful, loving experience and replace stress, fear and loneliness with teamwork, courage and friendship. **For more information, please consult the following:**

### **ShareTheCaregiving Inc.**

A Project of the National Center for Civic Innovation (501c3)

Website: **[www.sharethecare.org](http://www.sharethecare.org)**

For information, videos, resources, and links to purchase the book and for 23 forms available for download

Email: **[Info@sharethecare.org](mailto:Info@sharethecare.org)**

Guidebook: Share The Care™, How To Organize A Group To Care For Someone Who Is Seriously Ill.

By Sheila Warnock and the late Cappy Capossela, Simon & Schuster - A Fireside book 1995, 2004



**“The partnering of a patient and a loving caregiver with a health care team not only ensures the best patient care, but will be the foundation for transforming American health care.” — Richard G. Bennett, M.D., president, Johns Hopkins Bayview Medical Center**

## CAREGIVER TRAINING

You may not be 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 an issue, especially since most care recipients are elderly or disabled in some way.

You may find it helpful to locate books, DVDs/videos, Internet resources or workshops offered in your community on topics that are relevant to your situation. You may need to educate yourself about the following:

- Caring for someone with 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 or the care recipient's 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 and stress reduction





## FAMILY CAREGIVER TRAINING RESOURCES

The American Red Cross has developed a training program and reference guide for family caregivers that includes nine topic-based modules for caregivers, including:

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

Visit **www.redcross.org** and search “family caregiving,” or contact your local Red Cross chapter for more information on its caregiver programs.

### **The following are additional family caregiving training resources:**

Medicare (and Medicaid in some states) will pay for some types of caregiver education if it's provided as part of a patient's medically necessary in-person visit. Ask your health care provider for more information.

The Family Caregiver Alliance National Center on Caregiving provides fact sheets, discussion groups, telephone conferences, and other educational resources, including the Family Care Navigator, which provides state-by-state information on caregiving resources. For more information, visit the FCA website at **www.caregiver.org**.

The National Family Caregiving Association provides a virtual library of educational resources on its website, **www.nfcacares.org** under Caregiving Resources.



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.

The Arc of the United States ([www.thearc.org](http://www.thearc.org)) provides information on its website for families raising children with mental retardation and related developmental disabilities, including an online Family Resource Guide with state-by-state information.

AARP offers free online seminars and educational resources on multiple aspects of family caregiving, including the comprehensive, multimedia AARP Caregiving Toolkit (go to [www.aarp.org](http://www.aarp.org) and search “caregiving”).

The Chicago-based company Mather LifeWays offers CARE Coaching Online and other support programs. Visit [www.matherlifeways.com](http://www.matherlifeways.com) and click Institute on Aging for more information.

The National Association of Social Workers offers educational resources on its Help Starts Here website, [www.helpstartshere.org/seniors-and-aging/caregiving](http://www.helpstartshere.org/seniors-and-aging/caregiving).

Powerful Tools for Caregivers (PTC), a 6-week educational program, is delivered in communities across the US. Search the Internet for a PTC course near you.

## TRANSITIONS IN CARE: NAVIGATING THE HEALTH CARE MAZE

Transitioning from a health care setting, such as a hospital or skilled nursing facility, to home can be a confusing time for family caregivers and patients. This section provides tips to help.

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

- If your loved one has been hospitalized, make sure you speak with the discharge planner, who may be a nurse, social worker or other staff member, about the care plan before decisions are made. You should do this as soon as possible after a hospital admission because the stay will probably be short. Explore all the options, not just the one the discharge planner recommends.
- 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.
- One person from the insurance or managed care company (a case manager or a geriatric care manager) will probably be assigned to your loved one's case. 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. You don't always need the highest level. 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.

### NEXT STEP IN CARE™

If you are a family caregiver who has accompanied someone with a serious or chronic illness on the bumpy road from admission to discharge from a hospital, nursing home rehabilitation unit, or home care agency services, you know how chaotic this experience can be. Nothing can make these transitions in patient care settings stress-free, but understanding what is likely to happen can help bypass the most common barriers.

A website called Next Step in Care, available at [www.nextstepincare.org](http://www.nextstepincare.org), is designed to give family caregivers basic information to help them navigate an increasingly complex system.

As a family caregiver, you will probably be responsible for coordination of care yet family caregivers are rarely trained, supported, or included in transition planning. The Next Step in Care tools are intended to reduce confusion and anxiety as well as improve patient outcomes and reduce unnecessary re-hospitalizations.

Available in English, Spanish, Russian, and Chinese there are 30 guides all free and downloadable. They cover admissions and planning for discharge in three settings: hospitals, short-term nursing home rehab units, and home care services.

### **Identify and use all available resources.**

- Get to know your local pharmacist. Many people requiring care, especially people with chronic illnesses, take multiple medications. The pharmacist will help identify medication interactions and answer questions about dosing and side effects. Many problems following hospitalization are the result of medical errors. The Next Step in Care medication management guide (available at [www.nextstepincare.org](http://www.nextstepincare.org)) outlines some common problems family caregivers encounter and includes a simple, handy form to fill out and update to keep track of medication changes.

### **Take this form to all doctor appointments so that everyone has the same list, including over-the-counter medications.**

- Beyond Next Step in Care, familiarize yourself with print and Internet resources, especially about 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 who have experienced similar situations. Get to know people in your community and house of worship if you have one to learn what resources are available.
- Have friends and family help with paperwork, such as sorting bills, reviewing insurance policies, etc. Do not let bills and correspondence pile up.



### Caregiving and Depression

Some family caregivers experience depression, especially those providing intense personal care for many hours a day. Many caregivers report clinically significant symptoms consistent with depression. In addition, women are more likely than men to suffer emotional stress related to caregiving. Depression can persist long after a loved one has passed away or been placed in a care facility. If you are struggling with feelings of depression and anxiety seek help.

### Be firm but flexible.

- 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 firm but flexible 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 your family member's physician for a re-evaluation of the situation at a specified time (a few weeks or months).

### Expect Some “Out-of-Pocket” Expenses

Carol Levine, Director, Families & Health Care Project, United Hospital Fund, shares with us the following:

- Providing or managing the best possible care (e.g., changing dressings daily and providing other necessities) may be 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.”
- 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.

## 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. This is called respite care. Studies have shown that caregiving for prolonged periods can adversely affect both your physical and psychological health. It also can 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.

Take breaks as often as you can. Give yourself time every day to engage in a relaxing activity. Read a book, rest, take a walk or exercise, practice yoga, 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.

### **Several options might be available to you:**

- **In-home respite** — Ask a family member or friend to stay with your loved one so you can take care of your own responsibilities or get together with friends. Some religious communities have volunteers who are trained to provide in-home respite care for a few hours. For a fee, home health services can provide a personal aide to stay with your loved one.
- **Adult day centers** — These centers provide daily care in a group setting for individuals who need supervision. If you need a longer period of respite, check with local nursing homes or assisted living facilities to see if they are able to care for your loved one for several days. See the resources at the back of this booklet.

### **Safeguard your own health and well-being.**

- Go to your family physician for regular check-ups, mammograms or prostate exams. Let the doctor know that caregiving is an important part of your life.
- Take your medications as prescribed and monitor your own health with the same attention you give your loved one.
- Get a flu shot. You may also want to ask the doctor if you should receive the pneumonia vaccine. Supplies of the flu vaccine often run short, so be sure to obtain one early in the flu season, including vaccinations against seasonal influenza and new strains. Late fall and early winter are ideal. Ask your health care provider about which vaccines are right for you.
- Find time to exercise regularly. Even short walks in your neighborhood can be beneficial to your physical and mental health.
- Take classes that focus on stress-reduction and coping techniques. You may find yoga, meditation and other relaxation techniques particularly helpful. Once you are familiar with these practices, you will find the ease and peace they create are always available by taking a moment during the day to check in and return to those feelings.
- Eat a sensible, healthy diet that includes fruits and vegetables.
- 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.**

Many 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. In New York, visit [caringkindnyc.org](http://caringkindnyc.org).



Many people find solace in sharing feelings and seeking emotional support from others who understand first-hand the challenges of caregiving. If it is difficult to get out to a support group meeting, you might find it helpful to connect with others on Internet-based Discussion Boards. Many caregiving websites listed in this handbook include such online communities for family caregivers.

### **Attend to your spiritual needs**

Spiritual practices are essential for caregivers. You want to support your loved one, but when you are called upon to give a lot of time, your energy will be drained, especially if you are also working. Maintaining a spiritual life is one way to find the renewal and strength you need to care for your loved one. We've pointed out the importance of prayer, meditation and taking time to rest. Writing about your feelings in a journal also is helpful.

And we can't emphasize enough that you shouldn't do this alone, that you need to build a network of friends and professional help so you can take time for yourself. It is important as well to make sure you have someone on the outside with whom you can express your feelings honestly. You should not feel guilty about anger, resentment and admitting to your exhaustion. Talk to a friend, clergy member, counselor or support group. Keeping your feelings to yourself causes them to fester.

The Rev. Marion A. Gambardella has spent more than 20 years helping others achieve wholeness through the integration of mind, body and spirit. Her *Spiritual Conditioning for the Family Caregiver* offers ways to meet the daily struggles of caring for a loved one using affirmations, meditation and non-disease specific support groups. This program is designed to introduce you to a daily self-care healing practice and therapeutic exercises to help in releasing the harmful effects of everyday stress, anxiety and tension. Through positive and restorative





affirmations, participants can use their own abilities to give lovingly while attending to their own spiritual and physical needs. Visit her website at [www.marionagambardella.com](http://www.marionagambardella.com) to read her Spiritual Conditioning for the Family Caregiver and other helpful posts.

HealthCare Chaplaincy Network is a national health care organization dedicated to helping people faced with illness, suffering and grief find comfort and meaning — regardless of religion or beliefs. Its website [ChaplainsOnHand.org](http://ChaplainsOnHand.org) was created to respond to the related spiritual issues and is based on professional chaplains' experience with helping others in the healing process. You can chat by phone or email with a chaplain who will listen and offer spiritual comfort and support, or you may submit a prayer request. Visit [www.healthcarechaplaincy.org](http://www.healthcarechaplaincy.org).

The Spiritual Care Association (SCA), an affiliate of HealthCare Chaplaincy, ensures effective spiritual care in all institutional and community settings both here in the U.S. and internationally. SCA educates, certifies and credentials chaplains to more positively impact the overall health of the individuals they serve.

## 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.



### **Financial Support for Caregiving on the Horizon**

In 2006, Congress passed the Lifespan Respite Care Act, which amended the Public Health Service Act to establish a program to assist states in developing affordable and high-quality respite care for family caregivers across the age span. For information about caregiver financial support and assistance, visit [agingcare.com](http://agingcare.com).

## THE COSTS OF CAREGIVING

Caregiving itself can have financial consequences for the caregiver. 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, 401(K) retirement contributions and health care coverage.

A 2011 MetLife study of caregiving costs to working caregivers found the percentage of adult children providing personal care and/or financial assistance to a parent has more than tripled over the past 15 years. Currently, a quarter of adult children, mainly Baby Boomers, provide care to a parent.

## CAREGIVER EMPLOYMENT

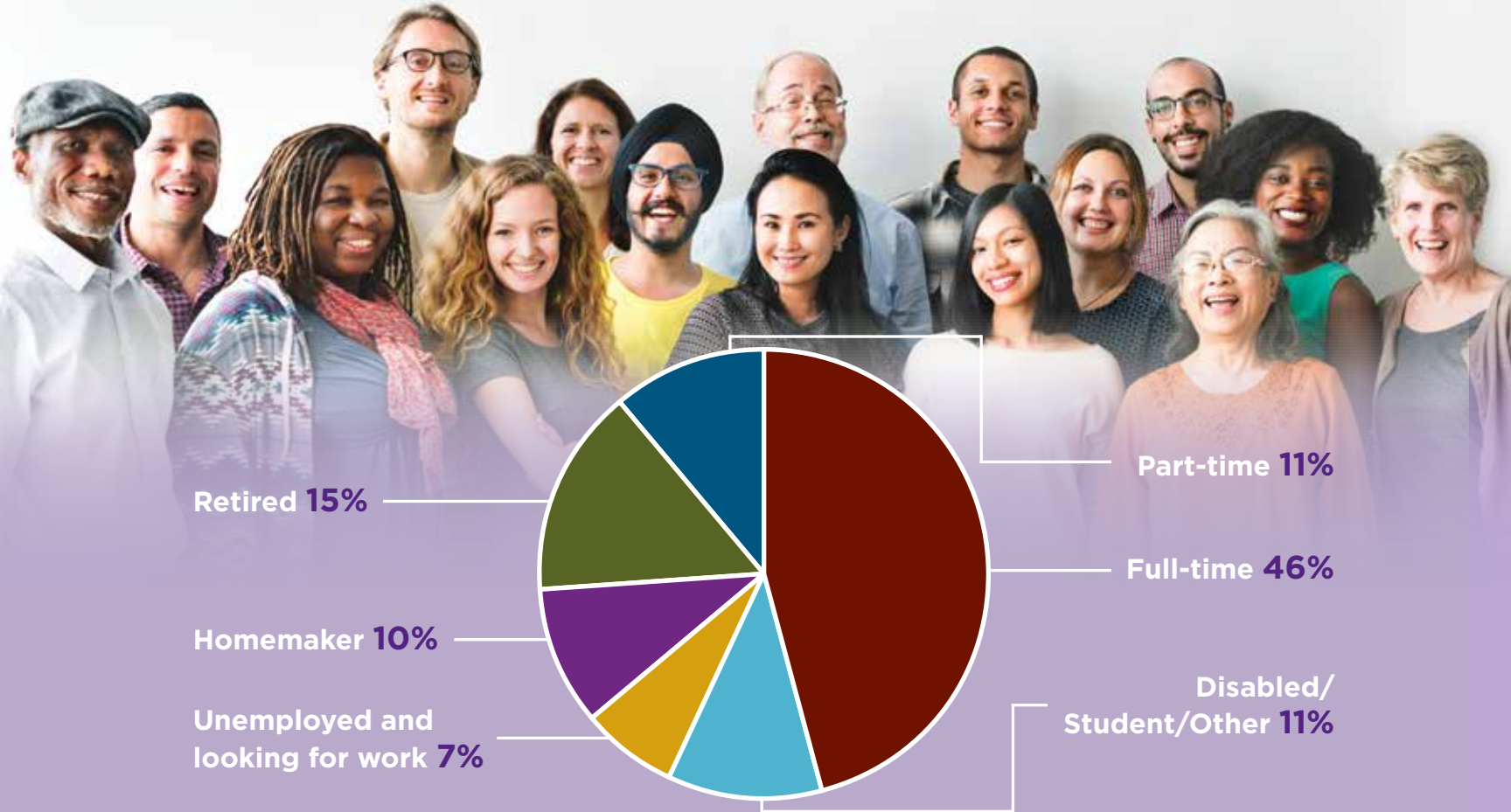
Caregivers typically spend about 24 hours each week caring for the recipient, which many people would consider the equivalent of an additional half-time job. As many caregivers work outside the home — three quarters (75%) are employed—caregiving duties represent a considerable time commitment. More than two-thirds of employed caregivers (70%) report that caregiving forced them to make changes at work, such as going in late, leaving early or taking time off during the day for caregiving responsibilities. Others leave their jobs altogether: 19% report quitting or taking early retirement.

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 unpaid leave from work. 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. To learn more about FMLA, visit the Department of Labor's website: [dol.gov/whd/fmla/employeeguild.pdf](https://dol.gov/whd/fmla/employeeguild.pdf).

# EMPLOYMENT STATUS OF CAREGIVERS

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





Recognizing that corporations are also financially impacted by having family caregivers among their workforce, EmblemHealth formed the NYC Partnership for Family Caregiving Corps (NYCP4FC Corps.) The Partnership presents customized offerings to help mitigate the impact on an organizations' bottom line by helping employees who are caregivers maintain productivity and thrive. For more information about the NYCP4FC Corps, visit [corporatecaregivers.com](http://corporatecaregivers.com).

Because a growing number of Americans have become family caregivers to wounded war veterans, the act was updated to implement new military family leave entitlements allowing a spouse, son/daughter, parent or next of kin to take up to 26 work weeks of unpaid leave to care for a member of the Armed Forces who is undergoing treatment, recuperating or otherwise disabled.

In 2015, New York Congresswoman Nita Lowey reintroduced the Social Security Caregiver Credit Act. This bill would improve the financial wellbeing of family caregivers by ensuring they are not forced to risk their retirement security by taking time out of the workforce to care for a loved one.

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.

## 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 should seek 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.

### ***Prepare 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.

- A power of attorney identifies the person who will make future financial decisions for your loved one.
- A health care proxy or medical power of attorney appoints an agent to make medical decisions for someone who can no longer make decisions for him or herself.
- 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.

Another important consideration is do not resuscitate (DNR), a legal order written either in the hospital or on a legal form. A DNR tells the medical team that you want to die naturally without heroic measures of ventilation, intubation, or vasopressor support. A DNR does not mean "do not treat" if a condition arises that could benefit from treatment such as IV fluids, antibiotics or oxygen.



Services and Advocacy for GLBT Elders (SAGE) is the country's largest and oldest organization dedicated to improving the lives of lesbian, gay, bisexual and transgender (LGBT) older adults. Visit [sageusa.org](http://sageusa.org) or [lgbtagingcenter.org](http://lgbtagingcenter.org).

*“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.”*



There are two kinds of DNR: an **in the hospital** DNR order means that if you stop breathing or your heart stops, nothing will be done to try to keep you alive. If you are in the hospital, you can ask your doctor to add a DNR order to your medical record. You would only ask for this if you don't want the hospital staff to try to revive you if your heart or breathing stopped. Some hospitals require a new DNR order each time you are admitted, so you may have to ask every time you go into the hospital. But remember this DNR order is only good while you are in the hospital.

**Outside the hospital:** Some states have an advance directive that's called a Do Not Attempt Resuscitation (DNAR) or special Do Not Resuscitate (DNR) order for use outside



the hospital. The non-hospital DNR or DNAR is intended for Emergency Medical Service (EMS) teams, who answer 911 calls and are usually required to try to revive and prolong life in every way they can. Even though families expecting a death are advised to call other sources for help when the patient dies, a moment of uncertainty sometimes results in a 911 call. This can mean unwanted measures are used. The non-hospital DNR or DNAR order offers a way for patients to refuse the full resuscitation effort in advance, even if EMS is called. It must be signed by both the patient and the doctor.

### ***Be prepared***

To be prepared, find and organize birth and marriage certificates, divorce decrees, death certificates, insurance policies, citizenship papers, deeds, cemetery plots, funeral arrangements, income and bank statements, power of attorney documents and wills. You will most likely need some or all of these documents in the future. 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 assets and property should be distributed upon the event of the recipient's 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., **Schiff Hardin LLP** New York, NY



**Thank You**

## CONCLUSION

Your caregiving journey may be rewarding—and difficult. Remember, you are not alone as a family caregiver. Help is out there. You need to find it and take advantage of it.

Some things to take away from this booklet:

- Take charge of your life, and don't let your loved one's illness or disability always take center stage.
  - Seek support from other caregivers and connect to caregiving resources.
  - Pay attention to your own health needs.
  - Remember to be good to yourself. Love, honor and value yourself. You are doing a hard job and you deserve some quality time, just for you. Caregiving is a job, although one from the heart, so reward yourself with respite breaks often.
  - 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 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 will lead you in the right direction.
  - Caregivers often do a lot of lifting, pushing and pulling. Be good to your back.
  - Grieve for your losses, and then allow yourself to dream new dreams.
  - Stay connected with your faith community and spiritual practices. If you are not part of a faith community but have some spiritual concerns, talk to a chaplain for support.
- © Contributed by the National Family Caregivers Association and the National Alliance for Caregiving.

***Thank you for accepting the responsibility to care for your loved one. The caregiving journey is a constantly unfolding experience. We hope you realize now that you are not alone in it and that you have found resources to support you along the way.***

*November is National Family Caregivers Month. Look for special activities and events in your area throughout the month of November each year.*

## CAREGIVER RESOURCE GUIDE: WHERE TO TURN FOR HELP

### **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)

**Publications and Resources Available at [www.caregiving.org](http://www.caregiving.org)**

### **Publications for Caregivers & Caregiver Advocates**

- Caregiver's Guide to Hospital Discharge Planning
- Caregiver Self-Assessment Questionnaire
- Care for the Family Caregiver: A Place to Start
- Palliative Care: Complete Care Everyone Deserves
- Quarterly Caregiver Webinars, including topics such as Financial Planning for Caregivers, Engaging Family Caregivers in Your Coalition, and How Employers Can Support Family Caregiving
- Guidebooks to starting and sustaining a family caregiving coalition, including *Planting the Seed: Establishing and Growing Your Family Caregiving Coalition* (2013) and *Growing Your Coalition: What to Do After You've Planted the Seed* (2014)

## Alliance Reports and Research Papers

- On Pin & Needles: Caregivers of Adults with Mental Illness (2016)
- Caregiving in the U.S. (2015), including a companion report on caregivers age 75 or older and caregivers of adults with disabilities (age 18 – 49)
- Catalyzing Family Technology to Support Family Caregiving (2014)
- From Plan to Practice: Implementing the National Alzheimer's Plan in Your State (2014)
- Best Practices in Workplace Eldercare (2012)
- Multiple Sclerosis Caregivers Study (2012)
- The MetLife Study of Caregiving Costs to Working Caregivers — Double Jeopardy for Baby Boomers Caring for Their Parents (2011)
- e-Connected Family Caregiver Report: Bringing Caregiving into the 21st Century (2011)
- Alzheimer's Caregiver's Healthcare Costs Increase as Person with Dementia Declines (2011)
- What Made You Think Mom Had Alzheimer's? (2011) (PDF)
- The MetLife Study of Working Caregivers and Employer Health Care Costs (2010)
- Caregivers of Veterans — Serving on the Homefront (2010)
- Alzheimer's Caregiving in the US (2009) (PDF)
- Diabetes Caregivers Needs Assessment Survey (2009)
- Caregiving in the U.S. (2009), including a companion report on caregivers supporting children with disabilities and caregivers of adults with disabilities (age 18 – 49)

### **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)

### **Caregiver Action Network**

1130 Connecticut Avenue NW, Suite 300 Washington, D.C. 20036

PHONE: 1-202-454-3970

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

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

### **Next Step in Care**

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

### **Today's Caregiver Magazine**

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

### **Caring.com**

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

### **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**

#### **Homecare Onlinereet**

Suite H Freehold, NJ 07728 TOLL-FREE: 1-8

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**

Building 31, Room 5C27

31 Center Drive, MSC 2292 Bethesda, MD 20892

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)**

1901 L Street, NW, 4th Floor Washington, D.C. 20036

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)

**Benefits Check Up**

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

**National Association of Professional Geriatric Care Managers**

3275 West Ina Road, Suite 130

Tucson, AZ 85741-2198

PHONE: 1-520-881-8008

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

**Mental Health**

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

3803 N. Fairfax Dr., Suite 100 Arlington, VA 22203

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**

2000 N. Beauregard Street, 6th 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: 1-866-699-1246

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

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

### **New York Family Justice Center**

Call 311 online, by texting 311-692, or by calling 3-1-1 from within the City or (212) NEW-YORK outside the five boroughs. TTY service is also available by dialing (212) 504-4115.

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

### **Respite Care**

National Adult Day Services Association, Inc.

85 South Washington, Suite 316 Seattle, WA 98104

TOLL-FREE: 1-877-745-1440

PHONE: 1-206-461-3218

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

PHONE: 1-919-490-5577

FAX: 1-919-490-4905

TDD: 1-919-490-5577

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

### **Eldercare Locator Search (For respite care and other services)**

INFORMATION LINE: 1-800-677-1116

WEB: [www.eldercare.gov/Eldercare.NET/Public/Home.aspx](http://www.eldercare.gov/Eldercare.NET/Public/Home.aspx)

## **Hospice**

### **Hospice Foundation of America**

1710 Rhode Island Ave, NW

Suite 400

Washington, DC 20036

PHONE: 1-800-854-3402

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

EMAIL: [haoffice@hospicefoundation.org](mailto:haoffice@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)^**

1731 King Street, Suite 100 Alexandria, VA 22314

NHPCO HELPLINE: 1-800-658-8898

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

**Center to Advance Palliative Care**

1255 Fifth Avenue, Suite C-2, New York, NY 10029

PHONE: 212-201-2670

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

**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)

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

1577 Spring Hill Road, Suite 220, Vienna, VA 22182

PHONE: 1-703-942-5711

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

**Financial Planning Association**

PHONE: 1-800-322-4237 FAX: 1-303-759-0749

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

## REFERENCES

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Facebook.com/careforthefamilycaregiver

emblemhealth.com/careforthefamilycaregiver

### **EmblemHealth**

Twitter.com/emblemhealth

Facebook.com/emblemhealth

blog.emblemhealth.com

### **New York City Partnership for Family Caregiving Corps**

corporatecaregivers.com

### **AdvantageCare Physicians**

AdvantageCare Physicians, a partner of EmblemHealth, provides high quality, coordinated, primary and specialty care at 36 convenient locations. For more information and to schedule an appointment, visit **acpny.com**.







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We wish you well on your caregiving journey.

Sincerely,

A handwritten signature in black ink, appearing to read 'Gregory L. Johnson', written in a cursive style.

Gregory L. Johnson  
Senior Advisor for Family Caregiving  
Office of the CEO  
EmblemHealth

A handwritten signature in black ink, appearing to read 'Gail Gibson Hunt', written in a cursive style.

Gail Gibson Hunt  
Founder and CEO  
NATIONAL ALLIANCE for CAREGIVING



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

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