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MARCH 2010 EDITION

CARE for the FAMILY CAREGIVER: A Place to Start

PREPARED BY:

EmblemHealth®

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NATIONAL ALLIANCE FOR CAREGIVING

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Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. 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

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EMBLEM HEALTH

At EmblemHealth, we are proud of our work supporting the family caregiver. We recognize that few jobs are as demanding as caring for a chronically ill or disabled loved one. Research shows that the burdens of being an unpaid family caregiver increase the risk for physical and emotional problems, particularly depression. That's why EmblemHealth has a long tradition of service for these "silent patients" who play a vital role in health care, but whose needs are largely ignored by the health care system.

As a founding member of the New York City Family Caregiver Coalition, EmblemHealth is committed to helping caregivers access the information and support they need to keep from becoming care recipients. In response to the Coalition's outreach to families of returning war veterans, we created a caregiver toolkit, which is appropriate for all caregivers. The toolkit can be found on our Web site and is included in the handbook supplement..

Our Care for the Family Caregiver Program, an initiative of EmblemHealth's Integrative Wellness department, promotes overall wellness—of the body, mind and spirit. By emphasizing self-care and lifestyle modification, our activities encourage EmblemHealth members to become more aware of the connection between the mind and body, and to appreciate the growing scientific evidence that each of us has the capacity to control stress and harness the healing power within. Visit emblemhealth.com for more information on these initiatives, including links to New York City, New York State and national caregiver organizations.

—Anthony L. Watson, Chairman and CEO

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Care for the Family Caregiver: Help Along the Way
Caregiving Advocates and Resources

Know that as a caregiver, you are not alone. In fact, experts estimate that more than **65 million** Americans are caregivers to adult friends or family members.

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 a 2009 survey found that 65.7 million people in the United States, or 28.5% of the population, serve as unpaid caregivers to an adult family member, a child with special needs 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, create a bookmark list of Internet sites 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

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 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. ✱

Family caregiver stories

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 16.8 million 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. 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. ✱

Family* caregiver stories

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. ✱

Family caregiver stories

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 help 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.

Unfortunately, Roxie is not alone. Experts estimate that 1.3 to 1.4 million children aged 8-18 care for an adult relative, 72% of whom care for a parent or grandparent. ✱

Nearly one-third of Americans, or 28% of the US population, serves as a caregiver.

The typical American caregiver is a woman who works and spends 20 hours a week providing care.

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 (nonpaid), family caregivers.

The face of the family caregiver

Caregivers are all around us. More than 65.7 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. Nearly a third of American households report that at least one person has served as an unpaid caregiver in the past year.

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 have increased. The average age of a caregiver is 49. More than half of all caregivers are between 18 and 49 years old, but there's been a recent shift upwards in caregivers who are between 50 and 64.

The majority of family caregivers are women (66%), although men also serve as caregivers. 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. Caregiving remains largely a woman's responsibility, as a considerable number of American women find themselves employed full-time in addition to caregiving 20 hours a week—the equivalent of a second part-time job.

Some differences have been reported in caregiving among different ethnic groups. For example, Hispanic caregivers are typically younger than white and African-American caregivers. African-American caregivers are more likely to have a lower household income, and Asian-American caregivers are equally likely to be male or female. Experts have noted that cultural and ethnic differences may influence expectations on family caregivers.

What tasks do family caregivers typically do?

In the 2009 Caregiving in the United States survey by the National Alliance for Caregiving and AARP, caregivers reported helping the care recipient with the following:

- Transportation
- Housework
- Grocery shopping
- Preparing meals
- Managing finances
- Helping with medication (e.g., administering pills, giving injections)
- Arranging or supervising paid services

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

- Getting in and out of bed and chairs
- Getting dressed
- Helping bathe or shower
- Getting to and from the toilet
- Feeding the care recipient
- 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 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 11% live in a nursing home or assisted living facility.

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 about $375 *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. Those who care for children with special needs are also recognized as family caregivers as their responsibilities are unique and more time-intensive than general parenting.

"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. 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
- Chronic diseases associated with ongoing disability, such as diabetes, severe arthritis, HIV/AIDS

The Graying of America

People aged 65 and older continue to be among the fastest growing segment of the US population. One in eight Americans are 65 or older, and their numbers will double between 2000 and 2030.

Many reasons have been cited for these differences, including declining fertility and the aging "Baby Boom" generation. Another reason? Longevity. More Americans are living longer. By the time the Baby Boomers begin reaching 85 in 2031, 21 million Americans will be 85 or older, compared with 6 million in 2010, a number that had doubled since 1990.

Caregivers, and care recipients, will likewise become older, resulting in greater demands for resources and assistance.

Trends in caregiving

The American population is aging, particularly as the "Baby Boomers" near the age of 65 and our life expectancy increases. This "graying of America" is expected to substantially increase the need for at-home family caregivers for decades to come.

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 national and local advocacy groups and government programs 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 paid 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.

While the total number of hours of care delivered by caregivers each week decreased in recent years, caregivers who provide help with more than one activity of daily living increased. In addition, unpaid help for caregivers has increased. However, paid help for caregivers decreased for recipients younger than 65 and those without Alzheimer's or dementia, which has been attributed at least in part to the downturn in the economy which began in 2008.

The Internet and technology offer a bright source of hope and support for caregivers. Many now regularly turn to the Internet for information and resources. 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.

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. 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, and search Home Safety Caregiving Checklist.)

Get caregiver training.

Seek out 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.

Most care recipients (93%) 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; 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.

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. This information can help you with planning.

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 health care professionals use in discussing the case. Be calm but firm in advocating for being a part of the health care and support service decision-making team.

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

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.

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. For example, 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

Educational resources and training for family caregiving are available through various sources in the community. Training classes, books, videos and Web sites can help you with practical skills and strategies for providing care. Note some resources charge a fee, while others are free.

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
- General Caregiving Skills
- 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

Visit www.redcross.org and search "family caregiving," or contact your local Red Cross chapter for more information on their 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 Web site at www.caregiver.org.

The National Family Caregiving Association provides a virtual library of educational resources on their Web site, www.nfcacares.org under Caregiving Resources.

The Arc of the United States (www.thearc.org) provides information on their Web site for families raising children with mental retardation and related developmental disabilities, including an online Family Resource Guide with state-by-state information.

The 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 and search "caregiving").

The Chicago-based company Mather LifeWays offers CARE Coaching Online and other support programs. Visit www.matherlifeways.com and click Institute on Aging for more information.

Medifecta Healthcare Training sells online seminars, DVDs, books and other educational programs for family and professional caregivers at www.medifecta.com.

The National Association of Social Workers offers educational resources on their Help Starts Here Web site, 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.

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.

Transitions in Care: Navigating the Health Care Maze

Patients, family caregivers and even health professionals often do not know what Medicare, Medicaid and health insurance will pay for. Family members and patients are frequently shocked to find when they are discharged from a hospital 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, many home care needs are covered only for an initial, short-term period or are not covered at all. This includes home health aides (HHAs) or personal care attendants (PCAs).

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.

Here are some tips to help you navigate the complicated health care maze.

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 very 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.
- 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.

The Next Step in Care Web site (www.nextstepincare.org), a new tool from the United Hospital Fund, helps family caregivers and health care practitioners provide safe and smooth transitions for patients.

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 medication errors. The Next Step in Care medication management guide (Available at www.nextstepincare.org) outlines some common problems family caregivers encounter and includes a simple, handy form to fill in and update to keep track of medication changes. You should 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 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 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 for a re-evaluation of the situation at a specified time (a few weeks or months).

Expect Some "Out-of-Pocket" Expenses

- Providing or managing 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."
- 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 or through another independent source.

- Contributed by Carol Levine, Director, Families & Health Care Project, 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. 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 way or been placed in a care facility. If you are struggling with feelings of depression and anxiety, seek help.

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 and 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, including vaccinations against seasonal influenza and new strains, such as H1N1. Late fall and early winter are ideal. Ask your health care provider about which vaccines are right for you.
- 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.

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) 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. 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 Web sites listed in this handbook include such online communities for family caregivers.

“**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.

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. As we entered 2010, a number of additional financial support measures were being considered for caregiving, including a tax credit for those who provide family caregiving and increased funding for national caregiver programs.

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.

A 2007 study found that half of caregivers caring for someone 50 years or older spent more than 10% of their income (an average of $5,531 per year) on caregiving. In addition, 34% of caregivers used some of their savings to cover caregiving costs. The economic downturn in recent years has also caused additional stress and financial concerns for family caregivers. Job losses, the inability to sell their own or a care recipient's home, and less resources in the community due to budget cuts have all taken a toll on family caregivers and recipients.

Caregiver employment

Caregivers typically spend 20.4 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—7 in 10 caregivers (73%) are employed—caregiving duties represent a considerable time commitment. Two-thirds of employed caregivers (66%) 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: one in five report taking a leave of absence; 6% quit working altogether; and 4% take 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 can also have a negative impact at work, leading to decreased productivity, greater

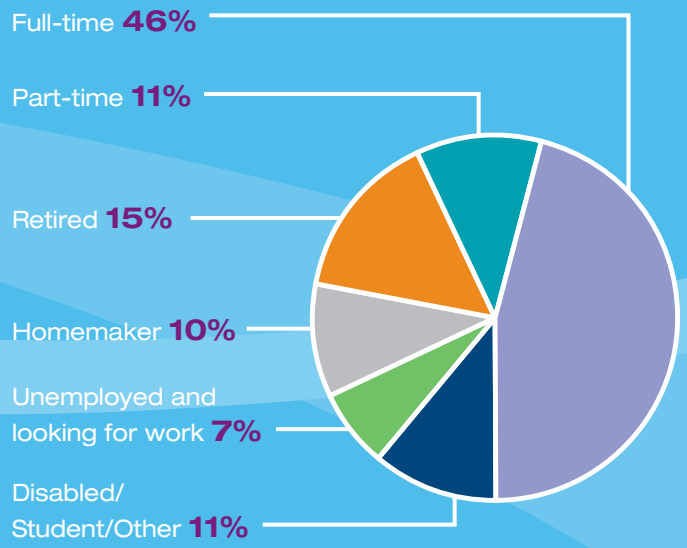
absenteeism and loss of work time. Maintaining employment is likely essential to your own financial future, and may also be a source of satisfaction.

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. 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 recent years, a growing number of Americans have become family caregivers to wounded war veterans. In January 2009, updates to the FMLA went into effect which implemented new military family leave entitlements. This new law allows 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 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 should 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.

✓ *Obtain 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 health care proxy or medical power of attorney appoints an agent to make medical decisions for someone who can no longer make decisions himself. 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 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., Mazur Carp Rubin & Schulman PC; 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. Caregiving is a job and respite is your earned right. 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 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.
- 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.
- 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
EMAIL: 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
EMAIL: 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
EMAIL: info@thefamilycaregiver.org

Today's Caregiver Magazine
WEB: www.caregiver.com

Family Caregiving Information
WEB: www.familycaregiving101.org

Caring.com Web site
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
EMAIL: 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
EMAIL: info@wellspouse.org

Housing

American Association of Homes and Services for the Aging (AAHSA)
WEB: www.aahsa.org

Homecare Online—National Association for Home Care and Hospice
WEB: www.nahc.org/Consumer/coninfo.html

Assisted Living Federation of America (ALFA)
WEB: 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

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

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
EMAIL: info@ncoa.org

Administration on Aging (US Department of Health & Human Services)
PHONE: 1-202-619-0724
WEB: 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

Medicare and Medicaid
PHONE: 1-800-Medicare
WEB: www.medicare.gov
Medicaid information available at:
http://www.cms.hhs.gov/home/medicaid.asp

Benefits Check Up
WEB: 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

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

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

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
EMAIL: info@alz.org

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
EMAIL: info@nadsa.org

National Respite Locator Service
WEB: 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
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.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
EMAIL: haoffice@hospicefoundation.org

Hospice Net – Information for Caregivers and Hospice
WEB: www.hospicenet.org/html/caregivers.html

National Hospice & Palliative Care Organization (NHPCO)
1731 King Street, Suite 100
Alexandria, VA 22314
WEB: www.nhpco.org
NHPCO HELPLINE: 1-800-658-8898

Legal and Financial Resources

Social Security Administration
PHONE: 1-800-772-1213
WEB: 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

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

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

Financial Planning Association
WEB: www.fpaforfinancialplanning.org

Women's Institute for a Secure Retirement (WISER)
WEB: www.wiserwomen.org/portal/

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Acknowledgements

Dear Caregiver:

There are many people who have generously made the creation of this resource possible. Many thanks specifically to all of the following who contributed their time and expertise to the development of this booklet:

- Michelle Flewell, CPLP, Medical Writer
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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
Director, Community Outreach
Creator, CARE for the
CAREGIVER PROGRAM
EmblemHealth

Gail Gibson Hunt
Founder and CEO
NATIONAL ALLIANCE
for CAREGIVING

CARE for the FAMILY CAREGIVER:

A Place to Start

MARCH 2010 EDITION
PREPARED BY:

CARE for the FAMILY CAREGIVER:
A Place to Start

To print additional copies of this report for your use, please go to the Web sites of EmblemHealth (www.emblemhealth.com) or the National Alliance for Caregiving (www.caregiving.org).

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CARE for the FAMILY CAREGIVER: Help Along the Way

Caregiving Advocates and Resources

PREPARED BY:

EmblemHealth®

nac
NATIONAL ALLIANCE FOR CAREGIVING

Next Step in Care™

A New Resource from the United Hospital Fund

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 new United Hospital Fund Web site called Next Step in Care, available at **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 after a stay in a hospital, nursing home, or after home care services end. 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 the guides are free and downloadable. Written in straightforward language, they cover admissions, planning for discharge, and discharges in three settings: hospitals, short-term nursing home rehab units, and home care services. One of the most important guides is called "What Do I Need as a Family Caregiver?" It lists many tasks commonly required after a hospital or rehab stay and recommends that the family caregiver consider as honestly as possible his or her abilities and limitations. The caregiver can check one of three responses: I am able to help WITHOUT training, I am able to help WITH training, and I am unable to help.

Next Step in Care™
Family Caregivers & Health Care Professionals Working Together

Another useful guide available on the Next Step in Care Web site is "Going Home: What You Need to Know," a checklist for discharge planning that allows you, along with the discharge planner, to list all the people and services you will need at home.

Gail Sheehy

AARP Ambassador for Caregiving

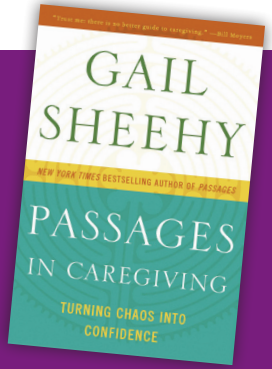
The best-selling author, award-winning journalist, and lecturer Gail Sheehy joined what she calls the "unpaid Army of family caregivers" when her husband was diagnosed with cancer. Since then she has become a tireless advocate for family caregivers.

After being named the AARP Ambassador for Caregiving in 2008, Ms. Sheehy embarked upon a tour through America to research her new book, *Passages in Caregiving, Turning Chaos into Confidence,* published by William Morrow/HarperCollins in May 2010.

Ms. Sheehy's new book on the caregiving crisis, which includes her personal story of 17 years as a caregiver, joins a distinguished list of her previous 15 published titles. Her earlier book *Passages* remained on The New York Times bestseller list for more than 3 years, and was named as one of the 10 most influential books of our times by a Library of Congress survey.

Ms. Sheehy's collaboration with AARP includes methods using new media. On her Web site, **www.GailSheehy.com**, the author presents videos of families she has filmed around the country who are finding creative ways around the obstacles of caregiving. Ms. Sheehy has been advocating for caregivers with private corporations, non-profit organizations, and government agencies, and will be lecturing around the country throughout 2010.

Additional information is available at the American Program Bureau website: **http://www.apbspeakers.com/speaker/Gail-Sheehy**



"Trust me: there is no better guide to caregiving." said Bill Moyers about Ms. Sheehy's new book *Passages in Caregiving, Turning Chaos into Confidence,* published by William Morrow/HarperCollins in May 2010.

"As a longtime champion for family caregivers, I am delighted that Gail Sheehy has brought this passage vividly to life from her own long experience and that of many others. Passages in Caregiving is one of those rare books that can drastically lighten even the heaviest of loads." – Rosalynn Carter, president of the Rosalynn Carter Institute for Caregiving

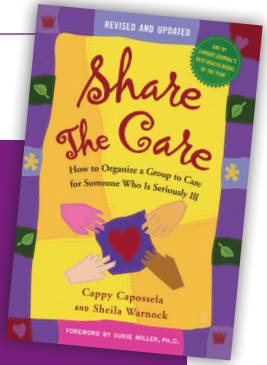
Visit **www.GailSheehy.com** for videos of her lectures and additional caregiving resources.

Share The Care™

A 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 tremendous task of caregiving alone. The Share The Care™ model has been empowering friends, relatives, neighbors, and co-workers across the U.S. and Canada with a step-by-step guidebook on how to create and maintain a "caregiving family" to assist someone they know and help to provide a better quality of life. A Share The Care group supports *not only* the care recipient, but *everyone* involved, including the family caregiver and their family, as well as each of the individual group participants.

For more information on this group caregiving resource, please consult the following:



ShareTheCaregiving, Inc.

HANDBOOK: *Share The Care, How to Organize a Group to Care for Someone Who Is Seriously Ill,* By Sheila Warnock and the late Cappy Capossela

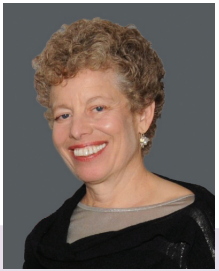
WEB: http://www.sharethecare.org
(all 23 forms of the handbook are available for download from the website)

EMAIL: info@sharethecare.org

Share The Care was born when a group of 12 women (mostly strangers to each other) came together and stayed together for three and a half years to care for a mutual friend with terminal cancer. Over time they developed ways of working and rotating responsibilities so no one person had too much to do. Their systems and color-coded forms were documented into the guidebook for caregivers and their concerned friends to follow.

Share The Care offers friends and family the best answer to the most frequently asked question "*What Can I do to Help*?" by showing the caregiver how to:

- Identify their "caregiver family" of friends, relatives, neighbors, business associates, and acquaintances.
- Introduce members of their extended caregiver group to the Share The Care system, which helps guarantee that every job will be done and no one person will have to do too much.
- Discover hidden talents within the group, make the most of their resources, cope with group issues and stay together 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.



Mary Mittelman, Dr.P.H.

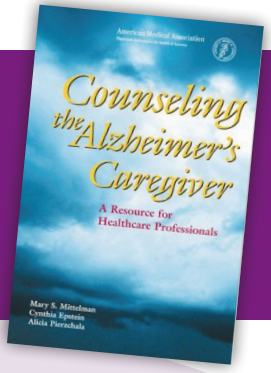
Alzheimer's Disease and Caregiver Researcher

Mary Mittelman, Dr.P.H., of NYU Langone Medical Center, is a leading researcher and author in the fields of Alzheimer's disease and caregiving. Her work focuses on rigorous scientific studies of ways to maintain the well-being of people with dementia and their family members through improved social support.

The Alzheimer's Disease International (ADI) and the Fondation Mederic Alzheimer recently awarded Dr. Mittelman the first global award for psychosocial research in Alzheimer's and dementia in recognition of the best evidence-based intervention for patients with dementia and their caregivers, the NYU Caregiver Intervention program. The NYU program offers individualized counseling for Alzheimer's caregivers and their family members that takes into account the differing needs of individual patients and caregivers and provides counseling support over the entire course of the disease. The book *Counseling the Alzheimer's Caregiver, A Resource for Healthcare Professionals,* which Dr. Mittelman wrote in collaboration with colleagues, features the unique NYU program and describes clinically researched strategies for counseling Alzheimer's caregivers. She received an award from the New York City Family Caregiver Coalition in 2009.

Counseling the Alzheimer's Caregiver

Features the NYU Caregiver Intervention program and describes clinically researched strategies for counseling Alzheimer's caregivers.



Dr. Mittelman's research focuses on the importance of psychosocial and social intervention, which includes improving dementia caregiving skills, mobilizing the support of family networks and caregiver counseling—all as an integral part of a comprehensive supportive approach. For more than two decades, her research has involved evaluating psychosocial interventions for family members of patients with Alzheimer's disease. She has coauthored several books for caregivers and professionals and numerous articles in the medical literature.

Dr. Mittelman serves as the director of the Psychosocial Research and Support Program at the Center of Excellence on Brain Aging NYU Langone, where she also is Research Professor in the Department of Psychiatry.

National Alliance for Caregiving

Publications and Resources Available at www.caregiving.org

Publications for Caregivers

- 7 Tips to Help your Parents with Medicare Part D
- Care for the Family Caregiver: A Place to Start
- Resources for Caregivers-2007 Edition
- A Family Caregiver's Guide to Hospital Discharge Planning (in English and Espanol)
- Palliative Care: Complete Care Everyone Deserves
- Family Care Resource Connection (available at: http://www.caregiving.org/fcrc.htm), which contains reviews and ratings of over 1,000 of the best books, videos, Web sites, and other materials on caregiving

Alliance Reports and Research Papers

- MetLife Study of Working Caregivers and Employer Health Care Costs (2010)
- Caregiving in the U.S. 2009
- Alzheimer's Disease Caregiving Advisory Board Meeting Summary (2009)
- Evercare®/National Alliance for Caregiving Survey of The Economic Downturn and Its Impact on Family Caregiving (2009)
- Evercare NAC Hispanic Family Caregiving in the U.S. (2008) English/Spanish
- Corporate Eldercare Programs: Their Impact, Effectiveness and the Implications for Employers (2008)
- MetLife Research Summit: Moving the Research Agenda Forward in Family Caregiving (2007)
- Evercare® NAC Caregiver Cost Study (2007)
- Caregiving in Rural America - A Report from Easter Seals and the National Alliance for Caregiving (2006)
- Evercare® Study of Caregivers in Decline (2006)
- The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business (2006)
- Young Caregivers in the U.S. (2005)
- Families Care: Alzheimer's Caregiving in the United States (2004)
- Findings on Communicating with Family Caregivers (2002)
- The MetLife Study of Sons at Work: Balancing Employment and Eldercare (2003)
- The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved (1999)
- Miles Away: The MetLife Study of Long-Distance Caregiving (2004)

Electronic Toolkit for Family Caregivers

EmblemHealth Recommended Web Sites

EmblemHealth's Care for the Family Caregiver Program was created to provide information, resources and tools to help manage the challenges and stress of family caregiving. The program recently created a new resource, the *EmblemHealth Electronic Toolkit for Caregivers*, which features ten important Web sites that we recommend to assist the caregiver, recipient, and their family and friends along their caregiving journey.

Originally created as an EmblemHealth contribution to the NYC Family Caregiver Coalition Veteran's Project, the toolkit has been positively received. Therefore, we are presenting these 10 recommended Internet resources herein for your benefit.

10 Recommended Caregiving Web Sites

1. **http://www.emblemhealth.com/PDF/CFC.pdf**
Care for the Family Caregiver; A Place to Start: written for the 2005 White House Conference on Aging; EmblemHealth and The National Alliance for Caregiving

2. **http://www.thefamilycaregiver.org/pdfs/10_tips.pdf**
10 TIPS for FAMILY CAREGIVERS, National Family Caregiver Association. EmblemHealth versions: English, Spanish, Russian and Chinese

3. **http://www.emblemhealth.com/default.aspx?Page=702**
EmblemHealth Care for the Family Caregiver web pages

4. **http://www.hipusa.com/downloads/intwellness/evidence_based_reality.pdf**
The Evidenced-Based Reality of Caregiving, an EmblemHealth publication

5. **http://www.n4a.org/about-n4a/?fa=aaa-title-VI**
Area Agencies on Aging; information by state

6. **www.nextstepincare.org**
Created by United Hospital Fund, practical family caregiver guides to improve patient transitions between care settings

7. **http://www.sharethecare.org/**
Share the Care: practical guide and steps to building a caregiving team/group

8. **http://www.cscs-ny.org/caregiver/index.php**
New York City Family Caregiver Coalition

9. **http://www.caregiving.org/**
National Alliance for Caregiving

10. **http://www.familycaregiving101.org/**
National Family Caregivers Association and the National Alliance for Caregiving. This non-profit Web site has been made possible by the generous support of Eisai, Inc.

CARE for the FAMILY CAREGIVER:

Help Along the Way

To print additional copies of this report for your use, please go to the Web sites of EmblemHealth (www.emblemhealth.com) or the National Alliance for Caregiving (www.caregiving.org).

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