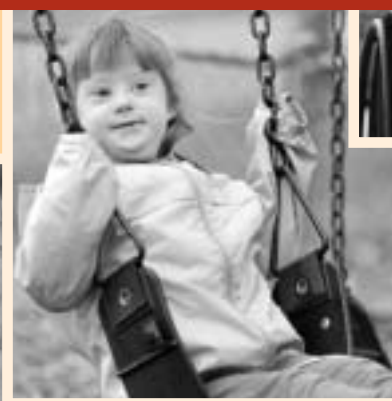


A PORTRAIT OF FAMILY CAREGIVING



NATIONAL
FAMILY
CAREGIVERS
ASSOCIATION

America's invisible workforce

Caregiving

is the issue of our age. Sooner or later, it will affect nearly every family in America. And we are not prepared to deal with it.

During any given year, more than 27 million Americans spend an average of 20 hours or more each week caring for a loved one who is disabled, frail, or suffering from a chronic condition. An estimated 30 percent of the current workforce has some responsibility caring for a relative—a number expected to increase to 54 percent by the year 2008.



Caregiving affects people of all ages, races, ethnicities, lifestyles and income levels. Usually untrained for the tasks at hand, and working without respite, family caregivers commonly sacrifice their own physical and mental health — and frequently their financial well-being — for the ones they love. While motivated by emotional commitment, they provide an invisible workforce that literally props up the American health care system.

The value of these family caregivers' services is estimated at \$257 billion a year — more than twice what is spent, nationwide, on nursing homes and paid home care combined.

Today, caregiving is much more than a family issue. It is a social and economic issue that warrants attention and action from policymakers, the health care industry and the public.

CAREGIVING AS A PUBLIC GOOD

Family caregiving is a public good as vital as firefighting or policing the streets. Family caregivers provide about 80 percent of all long-term care services in this country, often to their own physical and emotional detriment.

The work ranges from taking an aging parent to frequent doctors' appointments, to helping a developmentally delayed child learn new skills, to suctioning a spinal-cord-injured spouse virtually every hour every day.

Family caregivers can literally put their lives on the line to provide quality care to people they love. Research has shown that:

- Family caregivers can take longer to heal than non-caregivers, due to the effect of stress on the body's ability to heal itself.
- Elderly caregiving spouses who experience significant stress are 63 times more likely to die within a four-year period than non-caregivers.
- Family caregivers who help with personal care activities are more likely to suffer depression, sleeplessness, and backaches.



The stress of caregiving is often compounded by a lack of respite. When a family caregiver is no longer able to carry out her or his caregiving work, everybody suffers. The results may be disruption of family life and costly hospitalizations, or transfers to long-term care, such as nursing homes.

JON KEIMACH, LAKE ARROWHEAD, CA

There are nearly 3.2 million family caregivers in California. The estimated market value of their efforts is more than \$30 billion a year.

Jon Keimach figured at this point in his life as a single father, he'd be spending a lot of evenings rushing home from work to ferry his teenage son, Jonathan, to various school events.

Instead, Jon finds himself hurrying home from work to change his son's catheter. In August 2001, Jonathan broke his neck while riding his dirt bike. He is now a c4-6 quadriplegic.

Jon, 42, is Jonathan's primary caregiver. A specially equipped school bus picks up Jonathan, 16, each morning and takes him to school, where he's in the 11th grade.

Jon works full-time selling custom automotive wheels wholesale. His income has decreased because he's had to take off so much time from his business to care for his son. For now, Jon has hired the health aide from school to go to the house each day after school to change Jonathan's catheter. Once she leaves, Jonathan is on his own for a couple of hours before his father gets home from work.

"Ideally, he should have physical therapy several afternoons a week. He also could use a tutor a few days a week to help him with his homework. But I can't afford these things."

I don't mind the caring. I love him dearly and he has a great attitude...

Jon gets home from work between 6 and 6:30 p.m., makes dinner for the two of them, tends to Jonathan's toileting and helps him with homework. Jonathan usually goes to bed by about 9 p.m. because Jon must wake him at about midnight to give him medication, check his catheter and turn him. After that Jon finally goes to bed himself, usually about 12:30 a.m. The alarm is set to go off at 5:20 a.m. to start the daily routine once more.

He has spent countless hours trying to decipher what programs and services Jonathan is eligible for and to navigate the system to make sure his son receives those services. Jon has read that extensive, ongoing physical therapy and rehabilitation may help some quadriplegics, but such intensive services are not covered by his health insurance.

"I don't mind the caring. I love him dearly and he has a great attitude for what he has gone through. But I know for his long-term health, he needs a lot of physical therapy and rehab. I'm afraid he is literally going to lose years off his life because he's not getting these things."

MY WISH LIST

- **Access to affordable home health care, tutors and rehabilitation for physically disabled children.**
- **Affordable respite care to allow caregivers to take breaks so they don't burn out.**
- **A centralized system or center that people can turn to, to find out about what services are available for disabled children.**



CHANGES IN FAMILY CAREGIVING

Though family caregiving has been around as long as families, in recent times it has taken on new meaning. Fundamental changes in medical science, the health care system, and social norms have combined to create circumstances that have led to a growing need for, and dependence on, family caregivers. These changes include:

- **The rising cost of health care and the consequent reduction of services.** Patients are being sent home from hospitals “quicker and sicker.” Healing now occurs at home, and families are being asked to do what teams of health care workers once did.
- **Longer lives and different deaths.** In 1900, the average life span was just 47 years, and people commonly died of infectious disease. With the help of modern medicine, the average life span is now 77 years, and people commonly die of chronic conditions. This means caregiving situations typically last years or decades. Or, in some cases, such as when children are born with congenital abnormalities or developmental disabilities, caregiving can last an entire lifetime.
- **The “graying of America.”** As the baby boom generation ages, the fastest growing age cohort in the country is adults 85 years or older, and half of these people need at least some help with personal care. Their numbers are expected to grow from 4 million today to 19 million by 2050.

- **Larger numbers of working women; smaller, more dispersed families.** With more women working, it is no longer safe to assume they are available to provide home care. In addition, smaller families mean that the number of potential family caregivers is shrinking. In 1990, there were 11 potential family caregivers for each person needing care. In 2050, that ratio will be four to one.

Despite these huge changes, there has been little change in this country’s social service system. It is time to create policies to help family caregivers deal with their enormous tasks.

BEYOND THE FAMILY

Society needs a comprehensive approach to caregiving. While family, friends, and communities all have a role to play, only government has the wherewithal to make policy and law. A well-organized, affordable, and easy-to-access system is essential for care recipients and family caregivers to obtain the services they need.

Such a system must address at least two basic problems: the fragmented way in which health care and social services are provided, and the underlying philosophies of Medicare and Medicaid, which strictly limit options for those covered by either of these two major public health insurance programs.

I am 55 and the caregiver for my mother, Jane, who is 85 with Alzheimer's disease. I remained working for the first couple of years, sending mother full-time to senior adult day care. Unfortunately, she arrives home at 4 p.m., and, as she cannot be left alone, I have had to stop working.

—Susannah Blood, Kingston, RI

A FRAMEWORK FOR ACTION

Given these deeply rooted problems, policy-makers need to explore a range of legislative and regulatory approaches to support family caregivers. A basic framework would include the following goals:

Make Medicare more responsive to the service and support needs of individuals and families living with disabling and chronic conditions.

The nation's population is aging, with more people living for many years with multiple chronic conditions. To respond to this reality, changes to Medicare are essential.

Enable Medicaid to be more flexible in responding to the wishes of individuals and families living with disabilities and chronic conditions by expanding home and community-based options.

Today, Medicaid reaches 44 million Americans, more than Medicare or any other health insurer in the United States. Remove the built-in institutional bias that prohibits federal and state policy makers from shaping the program to respond to the growing demand for consumer-driven, and when appropriate, family-focused services.

Create easily accessible, reliable, and affordable state and national respite care systems to allow family caregivers of all ages a break from their duties.

Research shows that respite can help sustain marriages and family stability, as well as improve the quality of life of caregivers and care recipients.

Conduct a review of current tax policies and create meaningful strategies to ease the heavy economic burdens on family caregivers and caregiving families.

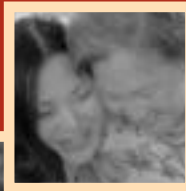
Caregiving families spend 2.5 times more on out-of-pocket medical expenses than do families in which no one is disabled.

Address family caregivers' ongoing need for education and support to ensure their ability to provide the best possible care for their loved ones.

Existing public and private programs that already have shown promise, including the National Family Caregiver Support Program, should be strengthened.

Urge the Institute of Medicine to undertake a comprehensive analysis of family caregiving and its repercussions.

The final report would include recommendations for policy and practices aimed at ensuring the health, safety, and well-being of family caregivers and care recipients. Such an analysis is vital for developing an integrated and unbiased view of the role family caregiving plays in our healthcare system and society.



People seeking health care and social services are largely on their own as they navigate the complicated and disjointed systems that deliver the care they need. For many, it is a process of trial and error that leads to conflicting advice from different providers, agencies and offices about the availability of services and eligibility requirements.

In addition, a patient with complex health problems may need to see multiple medical specialists. Without anyone coordinating care, each provider may prescribe different, and sometimes contradictory, treatments and medications. All this makes for confusion, delayed or inadequate treatment and support, and frustration for many patients and their families.

Add to this fragmented system the fact that Medicare, the federal health insurance program for older Americans, was designed primarily to address acute care situations, such as those requiring hospitalization, and Medicaid, the federal-state health program for the poor and disabled, pays for long-term care — but it is heavily focused on nursing homes and other forms of institutionalized care. For most people with chronic and disabling conditions, institutional care is a last resort. Neither of these two programs is designed to provide any relief to family caregivers.

MOVING FORWARD

It is time for America to change how it thinks about its more than 27 million family caregivers. They are pillars of the U.S. health care system and should be recognized as such.

Federal, state and local policymakers can lead the way. Some innovative programs and creative pieces of legislation aimed at improving the lives of caregiving families have been enacted at both the federal and state level. Yet, there is much more to be done.

As many Americans are discovering, family caregiving is not restricted to one time in life, one gender or one set of relationships. It is the work of caring for a child born with cerebral palsy, of a wife fighting ovarian cancer, of a brother paralyzed in a bicycle fall, of a lifelong partner breathing through an oxygen mask, of a husband losing his abilities to Multiple Sclerosis, of a mother losing her memory to Alzheimer's disease. Whatever the individual circumstances, family caregiving is a public good that requires and deserves public support.

We knew going into this it would not be easy. Some days are harder than others.... We are saving Medicare money by keeping my wife's parents at home with us, but we are spending our retirement savings. How about some help for us?

—Andy and Mickey Duplay, Monclova, OH



ELLEN MEJIAS, LAND O' LAKES, FL

There are more than 1.6 million family caregivers in Florida. The estimated market value of their efforts is more than \$15 billion a year.

In the 15-minute drive between her house and her parents' apartment, Ellen Mejias knows all the spots where it's safe to pull off to the side of the road and stop the car, so she can cry.

For nine years, Ellen, now 43, split her time between raising four children with her husband, Ed, and acting as caregiver for her parents, Joseph and Maria, who were in their 70s and lived nearby in their own apartment.

During that time, Ellen's father, Joseph, became increasingly disabled, as he suffered multiple strokes and was diagnosed with congestive heart failure, Parkinson's disease, and dementia. Ellen's mother, Maria, needed extensive assistance in caring for Joseph. So Ellen would go back and forth to her parents' apartment many times every week. By late 2002, Joseph had reached the point where he needed assistance with everything: dressing, bathing, toileting, eating, taking medications and getting around.

I just wish there were more resources, more places to turn for help.

For most of 2003, Ellen's daily schedule went something like this: Rise at dawn, get the kids, then aged 4 to 10, fed and ready, drop them at school or day-care, drive to her parents, get her father showered, dressed and fed, spend the day helping her mom tend to her father, prepare her parents' dinner, rush back to pick up the kids, take them home, help with homework, feed them dinner, do laundry, get them ready for bed, rush out the moment Ed got home from work to go back to her parents to help get her father ready for bed.

"I would go without practically any sleep," said Ellen. "I'd be driving home from my parents and I'd have to pull over and cry for a few minutes, just to let it out."

By fall 2003, Joseph's condition had worsened, and his doctors said he probably would not live much longer. The family decided to use hospice care, which is covered by Medicare.

Ellen's father died in late November 2003 at age 77.

"Believe me, I'm glad I was there for my father," said Ellen. "At the same time, I have to say caregiving is incredibly draining in every way — physically, emotionally, and financially. I just wish there were more resources, more places to turn to for help and guidance when you're in that situation, because it is completely overwhelming. It takes over your life."

MY WISH LIST

- **Someone to evaluate our situation and give us advice on better ways to handle things.**
- **A respite center where my parents and I could go on occasion.**
- **Funding to help caregivers pay for the out-of-pocket expenses that add up, such as for grab bars and bathroom assists.**
- **More assistance from local social service agencies and the faith community.**

FAMILY CAREGIVING AND PUBLIC POLICY: PRINCIPLES FOR CHANGE

This Statement of Principles was developed in 2003 by a collaborative group of family caregiver advocates to serve as a foundation for the development of public policy in support of family caregivers and their loved ones.*

PRINCIPLE 1

Family caregiving concerns must be a central component of health care, long-term care, and social service policymaking.

- Family caregivers put their own health and well-being at risk in the service of their loved ones while, at the same time, they save the health care system significant amounts of money.
- Despite the wealth of services they provide, and in spite of their staggering numbers, family caregivers continue to be the most neglected group within the health and long-term care system. In return for family caregivers' contributions to the public good, society, through its public and private sectors, must support caregivers through well-designed policies, programs, and practices.

The value of family caregivers' services is estimated at \$257 billion a year — more than twice what is spent, nationwide, on nursing homes and paid home care combined.

PRINCIPLE 2

Family caregivers must be protected against the financial, physical, and emotional consequences of caregiving that can put their own health and well-being in jeopardy.

- Out-of-pocket medical expenses for a family that has a loved one with a disabling or chronic condition who needs help with activities of daily living (eating, toileting, etc.) are more than 2.5 times greater than for a family without a family member with a disabling or chronic condition (11.2% of income compared to 4.1%).
- The majority of caregivers are employed and many are forced to make changes at work to accommodate caregiving. Over the course of a caregiving "career," family caregivers providing intense personal care can lose as much as \$659,000 in wages, pensions, and Social Security.
- Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high.
- Caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the rest of the population.
- The stress of intense family caregiving for persons with dementia has been shown to affect a person's immune system both in terms of increased chances of developing a chronic illness and in significantly slowing wound healing.

PRINCIPLE 3

Family caregivers must have access to affordable, readily available, high-quality respite care as a key component of the supportive services network.

- Respite, often the most frequently requested family support service, provides caregivers with occasional relief necessary to sustain their own health or attend to other family members. In emergency situations, a temporary haven to ensure the safety of the person for whom they provide care and provide them with a quality experience as well becomes an absolute necessity.
- Without respite, not only can families suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress associated with continuous caregiving.
- Respite has been shown to help sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect. Preliminary data from a recent study suggests that respite may also reduce the likelihood of divorce and help sustain marriages.
- Respite care remains in short supply for all age groups. In many cases, it is inaccessible to the family because of eligibility requirements, geographic barriers, cost, or the lack of culturally sensitive programs.
- Lifespan systems are needed to identify and coordinate federal, state and community-based flexible, high-quality respite resources and funding streams across ages, disabilities, and family circumstances.

PRINCIPLE 4

Family caregivers must be supported by family-friendly policies in the workplace in order to meet their caregiving responsibilities. Examples of family-friendly workplace policies include: flextime; work-at-home options; job-sharing; counseling; dependent care accounts; information and referral to community services; employer-paid services of a care manager and more.

- Currently, only large Fortune 500 companies tend to have programs to support family caregivers—and then only for those providing care for elderly relatives. Few small and mid-sized businesses, where most Americans work, have programs supporting family caregivers. And a growing number of businesses are reducing paid health benefits.
- Forty-two percent of parents of children with special needs lack basic workplace supports, such as paid sick leave and vacation time.
- Family caregivers are doubly penalized when they temporarily leave the workforce for caregiving. Not only may they lose actual pay, but they also lose social security credits, which can affect their own ability to care for themselves in the future.

Family caregivers provide about 80 percent of all long-term care services in this country, often to their own physical, financial, and emotional detriment.



PAULINE SODERMARK, CORINTH, ME

There are more than 128,000 family caregivers in Maine. The estimated market value of their efforts is more than \$1.2 billion a year.

Pauline Sodermark is worn out.

For 16 years, she has been the primary caregiver for her mother, Florence, who is now 99.

Florence, who lives with Pauline, has congestive heart failure, dementia, and she can barely walk, following complications from a long-ago broken hip.

A few years ago, Pauline's husband, Linwood, was diagnosed with Progressive Supranuclear Palsy, a rare brain disorder that causes serious problems with control of gait and balance, and can involve depression and mild dementia. Then last year, Linwood fell and broke his hip.

Now, Pauline takes care of both her mother and husband virtually all by herself.

Pauline, 62, retired from the federal government four years ago. "I had to stop working because caregiving was starting to become a full-time thing," said Pauline. "I'm fortunate I was a federal worker for so long because it allowed me to retire at an earlier age and still get a good retirement income and benefits."

But now that Linwood, 61, had to stop working because of his disorder, Pauline's retirement income has to support three people.

Caregiving is pretty much a 24-hour-day, seven-day-a-week job for me.

"I know we're more fortunate than a lot of people because we can afford the basics," she said. "But it gets tough sometimes. I can't afford home health care or anything like that. So caregiving is pretty much a 24-hour-day, seven-day-a-week job for me."

Florence's medical care is covered by Medicare, and Pauline and Linwood are covered under Pauline's health plan. But Pauline is concerned that the premiums for the health plan will become too expensive for her to keep paying before she and her husband become eligible for Medicare at age 65.

"I'm scared to death of losing our health coverage," she said.

MY WISH LIST

- **Having someone to assist with bathing my mother once a week.**
- **Having someone to take over the caregiving duties so I could have time to clean my house and keep up with the cooking and washing clothes.**
- **Sometimes, I just wish for a few minutes to myself in the daytime, instead of between 9 p.m. and 2 a.m., since that is when they are both sleeping and I am not in demand.**

Pauline acknowledges that she has neglected her own health in recent years because her focus has been on her mother and husband. "I know I'm overdue for a mammogram, but I can't go unless I can get someone to stay at the house for the afternoon."

"I'm proud that I've been able to take care of my mother and that I'm there for my husband," she said. "But I feel so pressured and I get so down sometimes. It's a lot to handle."



STACEY BARTZ, CEDAR FALLS, IA

There are more than 285,000 family caregivers in Iowa. The estimated market value of their efforts is more than \$2.6 billion a year.

It's the little things that get to Stacey Bartz the most.

"Putting butter on toast in the morning, opening a can of soup, chopping an onion. All of these things seem so simple," she said. "Normally, you wouldn't give them more than a few seconds thought. But for me these things are constant reminders that everything is different now."

Everything is different because on June 19, 2002, Stacey's husband, Barclay, suffered a stroke. As a result, Barclay, now 51, is unable to use his left arm at all. He can walk only short distances using a cane and a leg brace, and he needs help dressing and bathing. His short-term memory was also damaged. Stacey, 44, is her husband's primary caregiver. Barclay, who worked on the assembly line at a factory, had to retire on a medical disability pension and Social Security after the stroke.

"I'd like to be able to work part-time so I could be there for him more, but we could not get by without my full-time income."

Most people don't understand the obstacles we face in day-to-day living.

Stacey is quick to acknowledge the flexibility and understanding she has received from management and colleagues at her job in sales at a national company, where she has worked for 13 years.

For a short time after the stroke, home health aides would go to the house while Stacey was at work. But in-home care is expensive and not covered by insurance. Barclay now stays on his own during the day.

Stacey's days begin at 5 a.m. and do not end until late at night. At one point last year, Stacey became so physically and mentally worn down, she broke down crying and called her doctor's office, asking for help.

Her doctor helped arrange counseling and urged Stacey to attend support group meetings at the stroke rehabilitation center where Barclay goes for physical therapy.

"Most people don't understand the obstacles we face in day-to-day living," she said. "To be able to talk to others who are going through it, to laugh with them. It doesn't take away the daily struggle, but it helps to know that someone really gets it."

MY WISH LIST

- **Emotional and practical support for all caregivers, starting while the loved one is in the hospital.**
- **Government assistance to help support the family so a family member can stay at home and care for his or her loved one.**
- **Insurance that covers respite care.**
- **Referrals to support groups for all caregivers and care recipients so they have a place to go and not feel so all alone.**

PRINCIPLE 5

Family caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings.

- Family caregivers consistently report they were “not prepared” for their roles. This lack of training is most apparent when care recipients are discharged from hospitals or short-term nursing home stays after an illness or accident. One national survey found that 43 percent of caregivers performed at least one medical task, defined as bandaging and wound care, operating medical equipment, or managing a medication regimen. Yet formal instruction is sporadic and inadequate.
- Family caregivers’ need for information and training changes throughout the course of their loved one’s illness. They must have opportunities to learn new skills as they become necessary, access new resources, and learn about options for care as the situation changes. Families need honest information about the financial, social, and health-related consequences of various arrangements for care, and they must share in the decision-making about care arrangements.
- Professionals must provide information in understandable, nonjudgmental and culturally competent ways that reflect sensitivity to the caregiver’s emotional involvement with the care recipient.

PRINCIPLE 6

Family caregivers and their loved ones must have affordable, readily available, high-quality, comprehensive services that are coordinated across all care settings.

- People who need the assistance of family caregivers typically have complex, chronic medical conditions and functional limitations. As a

result, they require services from different parts of the medical and long-term care systems. Unfortunately, coordination of information and services within each system and between these systems rarely occurs.

- Use of community services increases with level of disability as well as with age. Thirteen percent of people over 85 use community services (home-delivered meals, transportation, care management, etc) compared to only one percent of persons ages 50–64. Case management services play an important role in linking individuals and families with available services as well as managing public spending for long-term services.
- Thirty-two percent of people with serious chronic conditions see four or more different physicians in a year. Medicare beneficiaries with five or more conditions see an average of 14 different physicians in a year.
- In 2000, 50 percent of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 percent reported that different providers gave other conflicting information. Another recent survey found that 44 percent of physicians believe that poor care coordination leads to unnecessary hospitalization. Twenty-four percent said poor care coordination can lead to otherwise unnecessary nursing home stays.
- It is in this environment that caregivers must take on the complicated and difficult role of care coordinator — ensuring that treatments prescribed by different providers do not conflict and ensuring that important medical and functional information travels across providers, settings, and over time. Care coordination — within the medical system and across medical and supportive service systems — is not common in health care today. Lack of coordination, resulting in poor health outcomes, can lead to inappropriate and potentially unnecessary spending.

PRINCIPLE 7

Family caregivers and their loved ones must be assured of an affordable, well qualified, and sustainable health care workforce across all care settings.

- Millions of family caregivers and their loved ones require medical and non-medical assistance from direct care workers, either at home or in institutional settings. A growing shortage of these paraprofessional and professional workers is affecting the quality and continuity of care. The problem is expected to worsen as the Baby Boom generation ages.
- A shortage of well qualified, reliable, and affordable health care workers has a direct impact on the health and safety of persons with chronic conditions or disabilities. It also has a direct impact on the health and well being of family caregivers who must pick up the extra workload, much of which requires training and support they do not have, and which adds to their caregiving burden.

The number of people aged 85 or older is expected to grow from 4 million today to 19 million by 2050.

PRINCIPLE 8

Family caregivers must have access to regular comprehensive assessments of their caregiving situation to determine what assistance they may require.

- Social service and health care providers cannot assume that family members can always provide care for a frail elder or person with disabilities.
- Family caregivers should be considered an integral part of the long-term care system, as individuals with rights to their own support and assessments of their own needs.
- An assessment of the family caregiver's strengths, needs and preferences provides the foundation for developing appropriate and quality long-term care.
- The availability of family members or others to provide uncompensated care should not be considered in allocating long-term care benefits (as in the Medicaid program).

**Authors of the Principles include: Lynn Friss Feinberg, National Center on Caregiving/Family Caregiver Alliance; Jane Horvath, Health Policy Analyst; Gail Hunt and Les Plooster, National Alliance for Caregiving; Jill Kagan, National Respite Coalition; Carol Levine, Families and Healthcare Project, United Hospital Fund; Joanne Lynn, MD, Americans for Better Care for the Dying; Suzanne Mintz, National Family Caregivers Association; Ann Wilkinson, Rand Corporation.*

The Principles, including endnotes, are available at www.nfcares.org and www.caregiving.org



SUSAN HAMBURGER, CHEVY CHASE, MD

There are more than 517,000 family caregivers in Maryland. The estimated market value of their efforts is more than \$4.8 billion a year.

Some people may dream of retiring in their late 50s, but it was the last thing Susan Hamburger wanted to do.

Susan, now 63, had no choice because she is the primary caregiver for her husband, Stan, who has advanced Parkinson's disease.

Stan, 69, was initially diagnosed more than 20 years ago. For several years, Stan's symptoms remained relatively mild. He worked as an epidemiologist with the Food and Drug Administration. Susan was a statistician for the National Institutes of Health.

In the last decade or so, as the Parkinson's progressed, the dynamic of the couple's relationship shifted.

"I have watched Stan go from an extremely bright man with whom I had a wonderful partnership to a cognitively impaired man who is unable to totally manage any aspect of his life," said Susan.

Susan kept working as long as possible, hiring a home health aide to stay with Stan for several hours a day. Using the Family and Medical Leave Act, Susan took as much unpaid leave as possible and arranged a flexible schedule with her supervisors at NIH.

You try to maintain your sense of humor...it's the only way to stay sane.

As Stan's disease worsened, she arranged to work full-time from her home office. Then, in 2000, Susan decided she had to retire. In the years since then, Stan's disease has progressed even further. Susan recently hired a woman for a few hours each weekday to help care for him.

"I'm very lucky that I can afford to hire help," she said. "Having someone come in and let you go off to do something on your own, even for a couple of hours, you can't imagine what a relief it is."

People who do not have a loved one in need of care often don't understand how overwhelming and draining family caregiving can be, said Susan.

MY WISH LIST

- **Recognition of the importance of caregivers in managing devastating illnesses in the home rather than in hospitals or nursing homes.**
- **Insurance coverage for incontinence products.**
- **Financial assistance/insurance coverage for home health care workers who provide the only breaks for many caregivers.**
- **Affordable day programs that provide stimulation and socialization for patients.**

"You try to maintain your sense of humor, because that's the only way to stay sane. But the reality is, this is hard work, and it's relentless, and we should not expect anyone to have to do it all alone," she said. "I know at times I have battled depression, anxiety, anger, impatience, frustration, fear and stress. Caregiving is the single most difficult thing I have ever done in my life."

PREVALENCE AND ECONOMIC VALUE OF FAMILY CAREGIVING: STATE-BY-STATE ANALYSIS

States	Number of Caregivers	Caregiving Hours per Year (Millions of Hours)	Annual Market Value (Millions of Dollars)
Alabama	434,289	465	\$4,099
Alaska	56,566	61	\$534
Arizona	488,129	523	\$4,607
Arkansas	260,432	279	\$2,458
California	3,184,776	3,412	\$30,056
Colorado	414,417	444	\$3,911
Connecticut	337,446	361	\$3,185
Delaware	76,822	82	\$725
District of Columbia	58,656	63	\$554
Florida	1,623,320	1,739	\$15,320
Georgia	778,491	834	\$7,347
Hawaii	119,576	128	\$1,128
Idaho	119,625	128	\$1,129
Illinois	1,193,025	1,278	\$11,259
Indiana	586,101	628	\$5,531
Iowa	285,579	306	\$2,695
Kansas	256,493	275	\$2,421
Kentucky	397,485	426	\$3,751
Louisiana	422,067	452	\$3,983
Maine	128,473	138	\$1,212
Maryland	517,124	554	\$4,880
Massachusetts	633,549	679	\$5,979
Michigan	958,512	1,027	\$9,046
Minnesota	472,445	506	\$4,459
Mississippi	268,262	287	\$2,532
Missouri	544,310	583	\$5,137

These state-by-state statistics on the *Prevalence and Economic Value of Family Caregiving* were developed in 2003 by the National Family Caregivers Association in conjunction with Peter S Arno, PhD, Department of Epidemiology and Social

Medicine, Montefiore Medical Center and Albert Einstein College of Medicine based on Dr. Arno's previous study, *Economic Value of Informal Caregiving: 2000* presented at the American Association for Geriatric Psychiatry conference, Orlando, FL., February 24, 2002.

States	Number of Caregivers	Caregiving Hours per Year (Millions of Hours)	Annual Market Value (Millions of Dollars)
Montana	88,154	94	\$832
Nebraska	163,857	176	\$1,546
Nevada	193,720	208	\$1,828
New Hampshire	121,467	130	\$1,146
New Jersey	831,953	891	\$7,851
New Mexico	170,908	183	\$1,613
New York	1,867,458	2,000	\$17,624
North Carolina	791,741	848	\$7,472
North Dakota	62,320	67	\$588
Ohio	1,107,578	1,186	\$10,453
Oklahoma	332,969	357	\$3,142
Oregon	336,491	360	\$3,176
Pennsylvania	1,229,219	1,317	\$11,600
Rhode Island	104,140	112	\$983
South Carolina	391,159	419	\$3,691
South Dakota	71,725	77	\$677
Tennessee	560,462	600	\$5,289
Texas	1,929,789	2,067	\$18,212
Utah	191,090	205	\$1,803
Vermont	60,506	65	\$571
Virginia	696,303	746	\$6,571
Washington	570,620	611	\$5,385
West Virginia	184,891	198	\$1,745
Wisconsin	520,561	558	\$4,913
Wyoming	47,569	51	\$449
Total	27,242,621	29,182	\$257,096



MYRA JENKINS, HUSSER, LA

There are more than 422,000 family caregivers in Louisiana. The estimated market value of their efforts is more than \$3.9 billion a year.

A couple of months ago, Myra Jenkins met her 22-year-old daughter, Amanda, for lunch.

It was the first time in more than three years Myra was able to have a leisurely meal out with her daughter.

In April 2000, Myra's husband, Ronnie, was diagnosed with Amyotrophic Lateral Sclerosis (ALS) at the age of 40. For more than three years, Myra took care of Ronnie almost entirely by herself, in addition to caring for her teenage daughter, Elizabeth, who has cystic fibrosis.

To help Myra with things she could not do herself, such as transfer Ronnie to and from his shower chair, Ronnie's father, brothers and several close friends would take turns stopping in once a day.

It took until June 2003, more than three years after the ALS diagnosis, to get a personal care attendant to help care for Ronnie for several hours each weekday. Ronnie qualified for the state program, but Myra faced many obstacles trying to arrange for the care.

I worry about how we're going to get by.

"We were on the waiting list for more than a year," she said. "I would call and be switched around to different people and different departments. Then one time when I called, I found out they had dropped Ronnie's name from the waiting list by mistake. So I basically had to start all over again."

Myra, 41, was divorced from her first husband and the father of her two daughters, in 1990. Four years later, she married Ronnie, a childhood friend. Ronnie had been paralyzed in a diving accident in college in 1981. By the time Myra and he married, Ronnie was quite independent, having built a successful career working for a life insurance and investment company.

The ALS drastically limited Ronnie's ability to do things himself. He had to retire from his job. Myra tried to continue to work part-time, but her schedule was sporadic because caregiving took so much time.

Even with health coverage, the out-of-pocket expenses have nearly depleted the couple's savings.

"I worry about how we're going to get by," she said. "But when you're a family caregiver, you basically have to take one day, or one hour, or, sometimes, one minute, at a time."

MY WISH LIST

- **Financial assistance for supplies, medication, and equipment that is not covered by insurance.**
- **Help in getting through red tape in government programs to get assistance so I may accomplish chores and other projects around the home.**
- **Help in finding a mobile RV company that could rent an RV that is specially equipped so we could go on a trip.**

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The personal stories included here were developed from submissions to the National Family Caregiver Story Project. This web-based NFCA initiative was developed to give family caregivers an outlet for expressing their thoughts and feelings and to create a database of stories that would bring to life the realities of what it means to be a family caregiver in America today. For more information on the story project go to: www.nfcacares.org.

The story project was begun in 2003 with a grant from the Christopher Reeve Paralysis Foundation.

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The National Family Caregivers Association (NFCA) is a grassroots organization created to educate, support, empower, and speak up for the millions of Americans who care for a chronically ill, aged, or disabled loved one. NFCA reaches across the boundaries of different diagnoses, different relationships, and different life stages to address the common needs and concerns of all family caregivers.