“There are only four kinds of people in the world — those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

— Rosalynn Carter, wife of former President Jimmy Carter
All around us today, family caregiving is a social issue that’s becoming more and more prevalent along with changes in the population at large. It concerns policymakers, politicians, employers, insurers, health care providers — essentially everyone. It is a major area of interest in faith communities and the subject of research in universities. Family caregiving is much more than an individual’s or a family’s issue. It is no less than the issue of our age and times, because sooner or later it will affect virtually every family in America (regardless of size or construct) and we are not prepared either as individuals or as a society to deal with it. Consider also that family caregivers have faced and decried the same struggles for decades, although continuing trends and changes are adding nuances to this already intricately sensitive issue.

America’s family caregivers are family, friends, partners, and neighbors. They come from all ages and all walks of life, and there are more of them now than ever before. They are also referred to at times as “informal caregivers” because they fit into the unpaid, unprofessional category, and a number have pointed out the inequity and misleading nature of this label. At a caregiver forum the Department of Health & Human Services (HHS) hosted several years ago, one advocate asserted, “There’s nothing ‘informal’ about what family caregivers do.”

Families throughout history have taken care of their chronically ill or disabled loved ones. Neighbors have helped neighbors if they did not have family around and communities have even helped care for the ill and dying among them; hundreds of thousands volunteer at hospices across the nation. However, the nature of caregiving has changed drastically over the years.

It is for all these reasons and more that the health care system isn’t equipped to handle or respond to the needs of caregiving families, and part of the reason that the National Association for Home Care & Hospice (NAHC) and other advocacy organizations like the National Family Caregivers Association (NFCA) are striving to assist family caregivers in their often extremely difficult and arduous endeavors and bring about changes in public policy to better serve them and their loved ones.

In the past, families did not:

- Provide care for as many years as they do now, with life expectancy climbing and the 85-and-over segment the fastest growing of the U.S. population;
- Care for loved ones who are as ill, aged, or disabled, with chronic care needs now having surpassed the need for acute care;
- Live in such a highly mobile society as we do now, with many families spread out over greater distances;
- Care for loved ones when so many women were employed and no longer staying at home;
- Wait until their thirties, forties, or beyond to have children, so that parents are often much older and may have need of care with comparatively younger and younger children, who themselves are thus at earlier stages of employment and less financially secure;
- Provide care at a time when health care costs and the question of who should pay for them were such an issue of concern;
- Provide care at a time when medical science had unlocked secrets about how to save and extend lives in ways that were previously unimaginable, thus further extending longevity but often at high accompanying cost; or
- Care for loved ones at a time when the average age of the population was climbing quickly and a great host of some 78 million baby boomers would soon be entering their senior years — an average of 10,000 boomers are now reaching retirement age every day.
The Costs of Family Caregiving

The amount that family caregivers spend out of their own pockets, the estimated hundreds of billions’ of dollars in uncompensated care they provide, and the costs absorbed by businesses related to caregiving are staggering, according to research conducted by the National Alliance for Caregiving (NAC), AARP and others stakeholder organizations.

In a 2007 compilation of studies by the National Alliance for Caregiving, AARP, the MetLife Mature Market Institute, and UnitedHealth Group long-term care unit Evercare that were cited at a Capitol Hill briefing, family caregivers’ median household income was initially pegged at $43,026 and average out-of-pocket costs at $5,531 annually for things such as household goods; food and meals; medical equipment and supplies; travel and transportation; medical copays; and pharmaceuticals. Notably, further study for particular segments of the groups showed that out-of-pocket spending had more than doubled, and this was before the effects of the recession took hold in recent years. Caregivers with lower household incomes (29 percent of the study group earned between $25,000 and $50,000 annually, and 22 percent earned less than $25,000 annually) still faced nearly identical amounts in out-of-pocket costs. Thus “the cost of care falls hardest on those who can afford it least,” Gail Hunt, president and CEO of NAC, observed at the briefing. Family caregivers, she said, “are under a great burden and undergoing a lot of sacrifice; they’re paying the money at a higher rate based on their income, and they’re also spending the time.”

That factor — time — was cited by caregivers in the study groups as the “most significant sacrifice” in caring for a loved one, although most caregivers noted that they give it willingly. Those providing 35 or more hours of caregiving each week said the effect is like “putting life on hold.” One couple that kept a study diary reported putting off their wedding due to multiple caregiving responsibilities.

Further study results showed that caregiving costs spiked to an average of $1,029 per month or $12,348 annually, more than twice the average annual out-of-pocket spending indicated by the study on the whole. Researchers could not account for this discrepancy, but speculated that one study group may have had lower incomes and been providing more-intense caregiving than the larger group polled. Or perhaps it was simply better accounting, similar to a common phenomenon in popular disease awareness such that certain diagnoses suddenly balloon very quickly: “When you write down things every day, you realize there’s a lot more going on there that you’re paying for,” Hunt noted.

According to the groups’ studies, personal sacrifices cited by caregivers included:

• Cutting back on leisure activities (49 percent) and vacations (47 percent);
• Saving less or not at all for children’s future (38 percent);
• Depleting own savings (34 percent);
• Skimping on basics such as clothing, utilities, and transportation (27 percent) or even groceries (25 percent); and
• Cutting back on own medical or dental expenses (23 percent).

Using those figures (assuming 1,080 hours/year), AARP calculated the annual cost of uncompensated care provided by family caregivers with varying per-hour rates:

<table>
<thead>
<tr>
<th>Cost of Caregiving per Hour</th>
<th>x 38 Million Caregivers (higher 2007 estimate)</th>
<th>x 30 Million Caregivers (lower 2007 estimate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>$19 (High, average private-pay cost for home health aide)</td>
<td>$780 billion</td>
<td>$616 billion</td>
</tr>
<tr>
<td>$14.70 (Medium, average wage for aides and other home health workers)</td>
<td>$603 billion</td>
<td>$476 billion</td>
</tr>
<tr>
<td>$9.04 (Low, median wage for all home health aides)</td>
<td>$371 billion</td>
<td>$293 billion</td>
</tr>
</tbody>
</table>

Source: AARP Public Policy Institute
In addition to monetary sacrifices, caregivers reported health-related strains, including:

- Heightened stress or anxiety (65 percent);
- Difficulty sleeping (49 percent);
- Increased financial worries (43 percent);
- Depression or hopelessness (37 percent); and
- New or worsening health problems (26 percent).

AARP sought to put a value on the cost of the uncompensated care that is provided by family caregivers. One problem the group encountered is that the definition of “caregiver” varies considerably, so for its purposes, AARP examined those aged 18 or older who provide care including assistance with at least one activity of daily living or instrumental activity of daily living for another adult 18 or older. The total number of adult caregivers estimated by AARP — which the group noted is conservative because it represents only those who were providing care at the time of the survey or within the previous month — was between 30 million and 38 million as of November 2006. Those caregivers provided an average of 21 hours of care per week, or 1,080 hours per year. Again, note that estimates of current adult family caregivers today are higher, ranging from about 45 to 65 million depending on criteria used to define the group.

The results indicated an annual total for uncompensated care of between $300 billion at the low end and $780 billion as a higher estimate. AARP then utilized conservative figures of $9.63 per hour for care, 34 million caregivers, and 1,080 average hours of care per year and calculated the total annual cost of uncompensated care from family caregivers at $354 billion. Putting things into perspective, that number was about equal to total expenditures under the Medicare program and exceeded federal and aggregate state spending on Medicaid.

## The Costs — Seen and Unseen

A MetLife Mature Market Institute study examined the cost of family caregiving borne by employers. Costs that businesses incurred related to family caregiving included replacement costs for employees who leave the workplace; absenteeism and partial absenteeism costs; costs due to workday interruptions, crises in care, or supervision requirements; costs associated with unpaid leave; and costs associated with reducing hours from full-time to part-time.

There are other costs related to adverse effects on the health of caregivers themselves. In fact, while each family caregiving situation is different, the NFC refers to the emotional strain and stress caregivers experience as the common, uniting factor. Study after study has suggested that family caregivers are at greater risk of disease and unhealthy behaviors, due in no small part to this stress and strain. “Employees in the U.S. who are caring for an older relative are more likely to report health problems like depression, diabetes, hypertension, or heart disease, costing employers an estimated average additional 8 percent per year or $13.4 billion annually,” according to the MetLife Study of Working Caregivers and Employer Health Care Costs (February 2010), which was produced in conjunction with the NAC and the University of Pittsburgh Institute of Aging.

Other study findings indicate that the additional cost effect of caregiving is more pronounced for younger employee caregivers between the ages of 18 to 39, who the researchers determined cost their employers 11 percent more for health care than do non-caregiving employees in the same age bracket. Looking deeper at its findings — including at the higher

### Key findings of the MetLife study:

- The total estimated annual cost to employers for full-time employees with “intense” caregiving responsibilities (i.e., providing assistance with personal care tasks such as bathing and feeding for an average of 12 to 87 hours per week) is $17.1 billion.
- The total estimated annual cost for all full-time employees with any level of caregiving responsibility is $33.6 billion.
- The average annual cost per full-time employee with “intense” caregiving responsibilities is $2,441.
- The average annual cost per full-time employee with any level of caregiving responsibility is $2,110.

incidence of diseases such as diabetes and depression among working caregivers — the study suggested that negative behaviors often are a product of the family caregiver’s burden.

“Eldercare may be closely associated with high-risk behaviors like smoking and alcohol consumption,” the study authors wrote. “Exacerbating the potential impact to employers is the possibility that these medical conditions may also lead to disability-related absences.”

Male working caregivers, who remain less common than female working caregivers, generally brought on the highest additional health care costs to their employers. The study found that male family caregivers in aggregate cost employers 18 percent more for health care than did non-caregiving employees.

Additional findings of this MetLife study include:

- Working caregivers age 18-39 “demonstrated significantly higher” levels/incidence of cholesterol, hypertension, chronic obstructive pulmonary disease, depression, kidney disease, and heart disease compared with non-caregiving employees within the same age group.
- Working caregivers report more difficulty in keeping up with their own health care, such as routine preventive care.
- As other studies have found, working caregivers were determined to have higher rates of absenteeism, which also adds up in terms of labor costs to employers. The study found that most of the differences in work days missed occurred in that younger employee age group, ages 18 to 39.

The study concluded that employers should embrace more support and flexibility for family caregivers. That includes offering employee wellness programs that help reduce stress and support health care and fitness needs as well as allowing caregiver employees to work more flexible hours to adjust for care they must provide or unforeseen needs of loved ones. Employers also should consider incentives such as lower health insurance premiums for workers who participate in preventive care and support such as annual physicals, mammograms, smoking cessation programs, and exercise regimens.

The bottom line is that caregiving places a hefty burden on caregivers themselves, both financially and in other ways, and also results in a significant expense to employers. Direct and indirect costs associated with family caregivers are, taken together, difficult to gauge, often unnoticed, and likely far larger than the enormous (and notably conservative) estimates that do exist. Were family caregivers suddenly to stop all that they do, the care they provide represents hundreds of billions in services if it had to be replaced or reimbursed and could not be absorbed by the already overburdened health care system.

How Can We Lighten the Load?

Three years ago, just prior to the epic debates over health care reform, the Centers for Medicare & Medicaid Services (CMS) convened a roundtable group of representatives from government agencies, consumer and health care trade organizations, and health care providers to confront the issue of family caregiving at the federal level. Charles Inlander, president of a health care marketing and communications firm, noted that the issue needed a much higher profile and pointed out that the loss of jobs and savings due to economic recession or higher cost-sharing for health insurance would make times even tougher for families already strained by the costs of providing care for a loved one.

“We have a system that fails the elderly and persons with disabilities largely because it’s focused on acute care,” contended attorney Peter Strauss, a fellow at the National Academy of Elder Law Attorneys. “And Medicare doesn’t cover long-term care. You all know this,” Strauss said, which leaves many paying privately for as long as possible and becoming impoverished to qualify for any long-term care coverage under Medicaid and other safety net programs. “A lot of these failures stem from a system that thinks that acute care is the only thing you need to look at,” Strauss reinforced. Because of the difficulties people already faced in
obtaining long-term care and support services, the nation’s economic troubles compounded matters.

The health care reform law enacted in 2010 contains provisions that are meant to help family caregivers or improve access to long-term care services and supports. For example, the Community Living Assistance Services and Supports (CLASS) Act championed by the late Senator Edward M. Kennedy was folded into the law. It creates an optional, private long-term care insurance program for working Americans that would provide a cash benefit if beneficiaries become disabled and require assistance with activities of daily living. However, many of these provisions have yet to take effect, and bringing the CLASS program into being is still theoretical, a work in progress. Although the Obama administration has continued to support the CLASS program, many questions remain concerning how to structure it and achieve financial sustainability against the backdrop of a catastrophic national debt ceiling or borrowing limit of $14.3 trillion.

But with all our present financial difficulties and complications, family caregivers’ problems are nothing new. At the CMS roundtable, a common theme expressed was that family caregivers have had to contend with the same issues for years. “The state of family caregiving in this country is dismal and it’s getting worse,” one advocate said. “These are the same problems that have been around for 30 years.”

Roundtable participants noted the following:

- **Financial incentives and assistance for families need to be determined and put in place, not just talked about.** Some participants suggested greater tax deductions for families providing care for a loved one, others said restrictions on home and respite care should be eased and coverage expanded, and some pointed out that employers need to get serious about allowing flexibility and other support for working caregivers. On that latter point, one participant said that caregiving for an elder parent “should be treated just like childcare,” support for which is more commonly found in the workplace.

- **Information meant to educate caregivers, seniors, and the disabled largely has failed.** While federal and state agencies as well as numerous organizations have invested in significant resources, caregivers and patients most often don’t know where to start, aren’t aware of support services in their communities, and end up confused and overwhelmed as they “start from scratch.” One more recent effort HHS put forth to help caregivers is the www.Medicare.gov/Caregivers website.

- **Home care must be expanded beyond what the current system allows.** Medicare covers only home health care under restrictions such as that a patient must be “homebound” and must require only intermittent care, and waivers to provide home and community-based, personal aide, and other services were limited under state Medicaid programs. However, some progress on that latter point may be seen since the health care reform law seeks to expand Medicaid home and community-based services and remove obstacles to waiver programs.

- **IT systems should be family caregiver-friendly.** The roundtable agreed that health IT must help facilitate and coordinate transitions between health care settings such as from hospitals to patients’ homes. Participants suggested that Health Information Portability and Accountability Act of 1996 (HIPAA) information re-
lease forms signed by patients should name the patient’s caregivers “and information should flow to them as well,” unless the patient specifies otherwise.

Given the economic difficulties the nation faces, the economic value that accrues from respite is obvious and substantial. Delaying nursing home or other institutional care placement of just one individual with a chronic condition for several months can save Medicaid, private insurance, or a family thousands of dollars.

At the congressional level, NAHC and numerous other organizations for years called on lawmakers to approve funding for respite care available to family caregivers through the Lifespan Respite Care Act. The law, enacted in 2007, authorizes competitive grants to states to make quality respite services available to family caregivers, regardless of age or disability. It also expands provider recruitment and training and family caregiver training. But Lifespan Respite languished for years without any funding appropriated to it.

However, in his fiscal year 2012 budget proposal, President Barack Obama called for $10 million for programs under the long-unfunded Lifespan Respite Care Act, $192 million for the National Family Caregiver Support Program, $8 million for the Native American Caregiver Support Program, and $13 million for Aging and Disability Resource Centers (ADRCs). ADRCs, which are jointly administered by CMS and the Administration on Aging, are intended to work in conjunction with Lifespan Respite and other programs by offering information and guidance to those seeking long-term care services and supports.

The law is based on model state systems to provide easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs; and assist family caregivers in locating, training, and paying respite care providers. These efforts have been cited as exemplary by the National Conference of State Legislators and highlighted by the National Governors Association, since helping keep

### Family Caregivers: Latest Estimates and Stats

- Some 65 million people, 29 percent of the U.S. population, provide care for a chronically ill, disabled, or aged family member or friend at some point during any given year and spend an average of 20 hours per week (and often more) providing care for their loved one.
- The value of the services family caregivers provide for “free” when caring for older adults is generally estimated to be $375 billion annually or higher.
- The typical family caregiver is a 49-year-old woman caring for her widowed, approximately 69-year-old mother. She is married and employed. About 66 percent of family caregivers are women. More than 37 percent have children or grandchildren under age 18 living with them.
- Some 1.4 million children and young adults ages 8 to 18 provide care for an adult relative. Nearly three-quarters of these, 72 percent, are caring for a parent or grandparent, and 64 percent live in the same household as their care recipient. Fortunately, most of these youths are not the sole caregiver.
- The average number of hours family caregivers spend caring for their loved ones is 20 hours per week, while 13 percent of family caregivers are providing 40 hours of care or more per week.
- Family caregivers are the foundation of long-term care nationwide, surpassing long-term care provided through Medicaid in every state.
- About half of care recipients live in their own homes, 29 percent live with their family caregiver, and 4 percent live in nursing homes or assisted living arrangements.
- More than one-third, 36 percent, of family caregivers care for a parent, and 7 out of 10 caregivers are caring for loved ones over 50 years old.
- On the pediatric side, 14 percent of family caregivers care for a special needs child, with an estimated 16.8 million caring for special needs children under 18 years old. More than half of these family caregivers, 55 percent, are caring for their own children.
- A majority 78 percent of adults living in the community and in need of long-term care depend on family and friends as their only source of care and support services.

Source: National Family Caregivers Association
family caregivers going with the right support and relief can stave off or even prevent the need for institutional care placement. The once-a-decade White House Conference on Aging in 2005, which gathered together leaders in long-term care and aging, also recommended support for the Lifespan Respite Care Act.

Given the economic difficulties the nation faces, the economic value that accrues from respite is obvious and substantial. Delaying nursing home or other institutional care placement of just one individual with a chronic condition for several months can save Medicaid, private insurance, or a family thousands of dollars.

**Home Care to the Rescue**

Most immediately, home care offers cost advantages compared with care in institutional settings, and evidence indicates the differential has been widening. According to a study just released by Virginia-based insurance and financial services firm Genworth Financial that examines health care costs over the last six years, the cost of in-home care remained largely stable compared to as much as a 5.7 percent increase for institutional care (Genworth 2011 Cost of Care Survey). But just as importantly, unlike other health care provider types, home care providers also have a unique and intimate “window” into the lives of the clients and patients they visit in the home and are often able to work more effectively in tandem with and educate family caregivers on disease management.

In Canada, home health providers use standardized assessment tools to help identify clients with a distressed family caregiver, defined as a spouse, adult child, friend, or neighbor who provides emotional support along with assistance in activities of daily living including shopping, transportation, medication management, bathing, dressing, and eating. Just like caregivers in the United States, many of Canada’s family care providers report experiencing distress, according to research released last year by the Canadian Institute for Health Information (CIHI). Corroborating findings of other studies on caregiver burden in the U.S. and U.K., CIHI’s study showed that family caregivers providing care for seniors with moderate to severe cognitive impairment, such as those with Alzheimer’s or other dementia, are most at risk.

“Many seniors want to stay in their own homes as they get older, and having a family member or friend provide informal care helps make this possible,” stated Nancy White, Resources for Family Caregivers from the National Family Caregivers Association

- **Tips and Tools:** Access NFCA’s tip sheets, “how to” guides, and other online tools designed to help family caregivers. [www.nfcacares.org/caregiving_resources/tips_and_tools.cfm](http://www.nfcacares.org/caregiving_resources/tips_and_tools.cfm)
- **Agencies and Organizations:** Find hundreds of caregiving websites and resources for insurance, training, respite, disease-specific information, and more. [www.nfcacares.org/caregiving_resources/agencies_and_organizations.cfm](http://www.nfcacares.org/caregiving_resources/agencies_and_organizations.cfm)
- **Caregiver Community Action Network:** Find info on this network of volunteers that works at the state and local levels to provide information, education, and support for caregivers. [www.nfcacares.org/caregiving_resources/caregiver_community_action_network.cfm](http://www.nfcacares.org/caregiving_resources/caregiver_community_action_network.cfm)
- **Health Care Information:** Access information on specific diseases, conditions, and symptoms such as cognitive impairment and hearing loss. [www.nfcacares.org/caregiving_resources/specific_conditions.cfm](http://www.nfcacares.org/caregiving_resources/specific_conditions.cfm)
- **Caregiver Depression:** Depression is significantly more common in family caregivers than it is in the general population. Caregivers can access ideas for coping with depression, a screening test, and other depression-related resources. [www.nfcacares.org/improving_caregiving/depression.cfm](http://www.nfcacares.org/improving_caregiving/depression.cfm)
manager of home and continuing care development at CIHI. “While caring for a loved one can be fulfilling, it can also be quite challenging. It is important to identify caregivers who are at risk of burnout, which can result in the senior’s being institutionalized.”

Canada’s home care staff flag clients with caregivers who become unable to continue providing care or who express feelings of anger, depression, or distress. Home care providers help ensure appropriate interventions to reduce the burdens of family caregiving, according to the study, which is intended to reduce inappropriate or premature admission to institutional care. In the United States, home care providers similarly help identify problems and provide greatly needed relief, education, and support to many of the nation’s unpaid caregivers. In many ways, family caregiving is a natural corollary to home care and hospice, and vice versa — the bond between them is remarkable.

**About the Authors:**

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