



# The Caregiving Exchange

*Supporting Caregiving Coalitions Across the US*

Fall 2006

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## News from the Alliance

**T**hanks largely to the support of our members, 2006 has been an exciting year for the Alliance. In November, the Alliance and MetLife Foundation recognized the efforts of six nonprofit organizations in supporting family caregivers as a significant part of their mission at a gala awards luncheon in Washington, D.C. National Family Caregiving Awards of \$25,000 were presented to each of the six organizations in three categories: caregiver education, technology, and caregiver support. A description of the awardees is presented in this issue of the newsletter. A description of the awardees' programs and how they achieved their success is profiled on our website at [www.caregiving.org](http://www.caregiving.org).

The *Pan American Conference on Family Caregiving* was held in Miami at the end of November. Delegates from eight Latin American countries – Argentina, Brazil, Chile, Colombia, El Salvador, Guatemala, Mexico, and Peru – participated in the conference to develop five-year plans for developing and enhancing programs for caregivers. The conference featured panel discussions on family caregiving policies and programs, good practice models, the role of coalitions in advocating for change in support of family caregivers, as well as roundtable working groups and how-to workshops. Pfizer was our principal sponsor for the conference. Other sponsors included Kimberly Clark, Johnson & Johnson Foundation, AARP Office of International Affairs, and the Pan American Health Organization.

In September, the Alliance and Evercare released the study *Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One*. The study is the first survey of the health impact of caregiving from the caregiver's perspective; it found that stress, depression, and sleep deprivation lead caregivers to neglect their own health, potentially jeopardizing both caregiver and care recipient. The report can be downloaded from our website. We released the Evercare study at our well-received *Conference on Caregiver Health as a Public Health Issue* on September 26.

Looking ahead to next year, the Alliance was awarded two grants to strengthen caregiving coalitions; one from the Retirement Research Foundation and one from the Langeloth Foundation. The grants will allow us to provide web-based advocacy training for 20 coalitions, to assist them in holding a Caregiver Awareness Day in their communities and, best of all, to hold the first national caregiver coalition conference. The conference will be held on March 5, 2007, in Chicago, as a pre-conference event to the ASA/NCOA annual meeting. The request for proposals from caregiving coalitions is presented in this issue of the newsletter. We hope all of you will submit a proposal to participate in this ground-breaking project.

Gail Gibson Hunt  
President and CEO

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## Request for Proposals from Caregiving Coalitions

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### I. Overview of the Project

The National Alliance for Caregiving is pleased to announce that we have received two grants from the Retirement Research Foundation and the Jacob and Valeria Langeloth Foundation to work with 20 caregiving coalitions throughout the U.S. This is a wonderful opportunity for 20 caregiving coalitions to participate in a ground-breaking project to strengthen your coalition, receive advocacy training, and participate in the first National Conference for Caregiving Coalitions on March 5, 2007 in Chicago, Illinois as a pre-conference program to the joint American Society on Aging/National Council on Aging annual meeting. The conference will provide an opportunity for your caregiving coalition to become part of a national network and to:

- Share best practices and lessons learned
- Learn to advocate for family caregivers in your community
- Develop strategies for long-term sustainability
- Create effective messages for community outreach
- Host Caregiver Awareness Day activities

Using webcast technology and telephone conference calls, the Alliance will train members of 20 caregiving coalitions in the use of the *Caregiver Coalition Advocacy Guide*. The training will take place over three webcasts scheduled for April through June 2007. A fourth webcast, tentatively scheduled for July 2007, will be conducted to provide training and technical assistance to enable caregiving coalitions to host Caregiver Awareness Days in their communities in November 2007.

### II. Commitment of the Coalitions

Caregiving Coalitions responding to this request for proposals (RFP) and participating in this project will have the opportunity to: 1) have at least one person from their coalition attend the first National Conference for Caregiving Coalitions on March 5, 2007; 2) participate in four webcast trainings; 3) participate in planning and hosting a Caregiver Awareness Day in their communities in November 2007; and 4) participate in an evaluation of the grant project.

### III. Commitment of the Alliance to the Coalitions

Each coalition participating in the project will receive a \$1,000 stipend for Caregiver Awareness Day activities, \$850 for travel expenses to attend the one-day meeting on March 5, 2007, and \$500 to help identify and survey a small sample of caregivers in their area as part of the evaluation.

### IV. Content of Proposals

To submit your proposal, please respond briefly to the questions below. Please limit your responses to no more than 3 pages. Proposals may be submitted in Word or PDF format by email to Aileen Worrell at [aileen@caregiving.org](mailto:aileen@caregiving.org). Proposals must be received by January 12, 2007. The Alliance will notify those coalitions selected to participate in the project by February 2, 2007. For additional information, contact Aileen Worrell at 301-718-8444 or [aileen@caregiving.org](mailto:aileen@caregiving.org).

*Request for Proposals continued on page 3*

## Tell us About Your Coalition

1. Who is the point of contact for your coalition (please include name, address, phone number, email address, and coalition website address, if applicable)?
2. When was your coalition started?
3. What is the purpose of your coalition?
4. Who are the caregivers served by your coalition (e.g., grandparents raising grandchildren, adults caring for aging parents, spousal caregivers)?
5. Approximately, how many caregivers does your coalition serve per year?
6. What type of services does your coalition provide?
7. What area is served by your coalition (e.g., city, county, state, regional, national)?
8. What type of staffing does your coalition have (e.g., paid staff, volunteers, board members)?
9. What types of organizations are members of your coalition?
10. How is your coalition funded?
11. Has your coalition conducted any activities to date? If so, what were the results of those activities?
12. Does the coalition have experience in evaluating or assessing coalition activities? If so, what have been the results of evaluations to date?
13. Does the coalition have a mailing list of caregivers in your area for a possible survey to be mailed to caregivers?
14. What are the future plans for your coalition?
15. What are the key challenges facing your coalition?
16. What training and technical assistance needs does your coalition have?
17. Can your coalition commit to participating in the activities outlined in Section II Commitment of the Coalitions above?
18. In 500 words or less, please respond to the question: Why do you want to be one of the 20 coalitions selected?

## National Conference for Caregiving Coalitions

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Join us for the first-ever **National Conference for Caregiving Coalitions** on Monday, March 5, 2007, at the Embassy Suites Hotel in Chicago, Illinois. This one-day conference will be held as a preconference event to the joint ASA/NCOA annual meeting on March 7-10, 2007. Funding for the conference was provided by the Jacob and Valeria Langeloth Foundation and The Retirement Research Foundation.

The conference will provide an opportunity for your Caregiving Coalition to become part of a national network and to:

- Share best practices and lessons learned
- Learn to work together to advocate for family caregivers in your community
- Develop strategies for long-term sustainability
- Create effective messages for community outreach
- Host Caregiver Awareness Day activities

Registration, which is complimentary, is limited to 75 attendees. Attendees should be members of a state or local caregiving coalition. For registration information and questions, send an email to [aileen@caregiving.org](mailto:aileen@caregiving.org). To register online, go to [www.caregiving.org](http://www.caregiving.org) and click on the link to register for the conference.

## Coalition News

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### New York City Family Caregiving Coalition Launched

On November 14, 2006, the **New York City Family Caregiving Coalition** (NYCFCC) was officially launched at a gala reception hosted by HIP Health Plan of New York, which drew over 200 attendees including the Commissioner of Aging for New York City. The coalition, sponsored by the Council of Senior Centers and Services of New York City, participated with the Alliance in a pilot-test of the *Caregiver Coalition Advocacy Guide: Uniting Voices, Building Community*, which was developed by the Alliance and Brian Duke, a consultant and Executive Director of the New Jersey Foundation on Aging. The event included a keynote address by **Carol Levine** of the United Hospital Fund (UHF) in which Ms. Levin launched UHF's policy agenda and ethical framework for public policy, both of which are available from UHF's website at [www.uhfnyc.org](http://www.uhfnyc.org). The Alliance and Mr. Duke were instrumental in helping form the NYCFCC and were recognized for their efforts at the official gala launch.

### Next Alliance/CMS Caregiving Coalitions Conference Call

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Our next quarterly Caregiving Coalitions Network conference call will feature another excellent interview with a coalition leader. Moira Fordyce, MD, of the California Coalition for Caregivers will discuss the evolution and work of the coalition. Moira is also the Clinical Professor of Medicine at Stanford University School of Medicine. Since the coalition was launched in April 2005, they have provided information to the California legislature on a Caregivers Tax Credit; conducted outreach with low-income communities to make them aware of the tax credit and how they can benefit from it; and developed policy recommendations for the coalition in the areas of public policy, marketing and communications, and education and programs among others. Be sure to join us on January 17 and learn how to strengthen your caregiving coalition. The call-in information and agenda are included below.

#### Call-in Information

Date: January 17, 2007

Time: 1 to 2 p.m. (Eastern Time)

Toll-free phone number: 1-888-322-3914

Passcode: Network

Call Leader: Spencer Schron, Centers for Medicare and Medicaid Services (CMS)

#### Agenda

1. Welcome to the Call: Spencer Schron and Gail Gibson Hunt, National Alliance for Caregiving (NAC) (5 minutes)
2. Request for Proposals from Caregiving Coalitions: Gail Hunt (10 minutes)
3. Medicare Update: Robert Boggio, CMS (15 minutes)
4. Dialogue on the Development of the California Caregiving Coalition: Moira Fordyce and Aileen Worrell, NAC (30 minutes)

## Legislative Update

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### Older Americans Act Amendments of 2006 (HR 6197)

The Older Americans Act Amendments of 2006 passed during the final days of the session of the before the Congressional recess. The bill reauthorized the Older Americans Act for another 5 years and increased the appropriation level to \$187 million over 5 years for the National Family Caregiver Support Program (NFCSP). In addition, the bill modified eligibility requirements for the NFCSP to:

- Provide caregivers services to an older adult who cares for a child of any age with a disability;
- Allow participation of a grandparent or relative caregiver beginning at age 55;
- Authorize caregiver support for relatives responsible for the care of an individual of any age who is diagnosed with Alzheimer's disease or a related neurological disorder.

### Lifespan Respite Care Act (HR 3248)

The Lifespan Respite Care Act was passed by the House and Senate during the November lameduck session and signed into law by President Bush on December 21, 2006. The new law would authorize \$289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Lifespan respite programs are defined in the Act "as coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs." Specifically, the law authorizes funds for:

- development of state and local lifespan respite programs;
- planned or emergency respite care services;
- training and recruitment of respite care workers and volunteers; and
- caregiver training.

## 2006 National Family Caregiving Awards Honor Non-Profits That Have Made a Difference

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Representatives from leading nonprofit organizations convened in Washington, D.C. on November 9, 2006 to honor the 2006 winners of the National Family Caregiving Awards, sponsored by the National Alliance for Caregiving with support from MetLife Foundation. The event recognized outstanding community agencies that support family caregivers providing assistance to older adults.

Nearly 170 nonprofit agencies competed for six national awards, which included categories for caregiver support, caregiver education, and technology. These agencies help family caregivers by providing support, education and other resources in the ongoing effort to assist vulnerable older adults to remain either in their own homes, or with family, as research shows that vast majority of Americans prefer to remain in their own homes as they age.

This year's award winners included:

*Family Caregiving Awards continued on page 6*

**Eldercare Partners** in West St. Paul, Minnesota was recognized in the category of Caregiver Support, for Eldercare Partners' caregiver services. This coalition of service agencies in Minnesota provides individual coaching and counseling for families.

**Mountain Empire Older Citizens, Inc.** in Big Stone Gap, Virginia was recognized in the category of Caregiver Support, for Family Support Services. This single agency in Appalachia has pulled together an extensive array of services for their broadly dispersed clients.

**Wisconsin Alliance for Family Caregiving** in Madison, Wisconsin was recognized in the category of Caregiver Education, for strengthening the delivery of family caregiver education through partnership. This statewide network of 75 organizations in Wisconsin works toward a common goal of supporting caregivers.

**The Stroke of Hope Club, Inc.** in North Palm Beach, Florida was recognized in the category of Caregiver Education, for its caregiver manual. This all-volunteer organization in Florida is committed to enhancing the lives of stroke "victims" and their caregivers.

**The Family Caregiver Alliance, in San Francisco, California** was recognized in the category of Technology, for its support of caregivers through the use of the latest technology. This organization is the nation's oldest caregiver organization, and uses technology in all of its efforts to get help to those in need.

**The Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties** based in Los Angeles, California was recognized in the category of Caregiver Education, for its Asian American Dementia Care Network. This southern California chapter of the nationally-recognized Alzheimer's Association targets and serves families of multiple Asian cultures. This organization was also honored with a special "*MetLife Foundation Excellence in Alzheimer's Caregiver Support Award*," for its commitment to improving the lives of those with Alzheimer's disease and their caregivers.

Nonprofit honorees were awarded \$25,000 to continue and enhance their support for caregivers. Applicants were asked to demonstrate how they are innovative, effective, replicable, based upon research, and responsive to diverse populations. Applicants were judged by a panel of experts, who selected six programs to be honored.

Two programs were also given honorable mention awards: the Mid-Missouri Chapter of the Alzheimer's Association, located in Columbia, Missouri, a support group in Missouri for male caregivers of women with Alzheimer's disease; and Area Agency on Aging 1-B, in Southfield, Michigan, an overnight respite program that allows families to leave their loved ones in a secure and caring environment.

More information on the competition and detailed profiles of the award winners can be found on the Alliance's website at [www.caregiving.org](http://www.caregiving.org).

## The Top Ten Things Caregivers Don't Want to Hear.... And a Few Things They Do

by Carol Levine, Director of the Families and Health Care Project

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I've been a family caregiver for my disabled husband for nearly 17 years, and in that time I've been given all kinds of unsolicited advice, unwelcome criticism, and undeserved praise. I've developed a thick skin and some stock replies. But, I wondered, am I alone in feeling frustrated at the insensitivity of some of these comments, particularly when they come from casual acquaintances or marginally involved professionals? Apparently not! I sent a query to the Alliance's Caregiving Listserv and other caregiving venues, and was deluged with responses.

I've edited, collapsed, and compiled the results, many of which match my own favorites but some of which relate to other situations. Not every response could be included and every caregiver will probably have a different list or a different ranking. Here then are my candidates (with a nod to David Letterman):

### **10** Doesn't Medicare (or your insurance) pay for that?

People who have no experience with long-term chronic care are unaware that Medicare and private insurance do not cover most of what is needed to keep a family member at home or in assisted living or nursing homes beyond short stays after hospitalization. Only Medicaid, which requires impoverishment, pays for long-term care, and even that program varies by state and is still biased toward institutional care. Enlightening the uninformed is tedious but perhaps serves an educational purpose. If these folks understood the financial burden and unending responsibilities of long-term care, then maybe they wouldn't say things like "Where are you going on your vacation? or..."

### **9** It must be hard to work and take care of your husband, so why don't you just quit your job?

My guess is that this is a question asked only of women, since men are presumed to have a greater personal and financial attachment to their jobs. Beyond the financial necessity, especially for women who are heads of households, work for many caregivers is an affirmation of their worth beyond caregiving, a source of friendship and stimulation, and a welcome balance to their lives. Others do leave the workforce, but at considerable cost to their current financial status and future retirement or employment opportunities. It's not a decision to be taken impulsively. A good friend or concerned family member can certainly help a caregiver weigh the options objectively.

### **8** Your mother belongs in a nursing home. OR: I could never put my mother in a nursing home.

This is one of those statements that offends either way it is offered. The first formulation suggests that the caregiver is not capable of providing good care, or that Mother is dispensable. The second is a clear criticism of the caregiver who, after considerable anguish, decides that the only solution is indeed a nursing home. Well-wishers should avoid making quick judgments, which mainly serve to make the caregiver feel guilty. There is a place, of course, for candid discussion about whether the caregiver can continue to provide care at home. (Big exception: If Mother is truly being neglected or abused, then a professional intervention is in order.)

*Top 10 Things continued on page 8*

## **7 You have to take care of yourself; your husband (mother, father) needs you!**

Of course, caregivers should take care of themselves; but why does it have to be linked to another person's need? Am I not worthy of good health for myself? And how exactly am I to find time to rest, exercise, prepare balanced meals, see the doctor, and do all the other things I should do? And if I don't do them and my health suffers, is it my own fault? Unfortunately, many caregivers do see themselves only as extensions of the person they are caring for, and still they don't take good care of themselves. And if a caregiver starts to explain why she doesn't follow all the good health rules, she is likely to be asked.....

## **6 Why don't you get your family to help out more?**

This deceptively simple question steps on a huge emotional landmine. Some families cooperate without any hesitation or difficulty; in others, sharing responsibility is fraught with emotional traps. Some caregivers choose, for their own reasons, not to rely on other family members; others would like the help but either don't get it or find it comes with too many conditions. A trained professional can mediate and perhaps work out an acceptable division of labor. When some family members are not closely involved in care, they may say things like ....

## **5 I don't see what you're complaining about. Dad seems fine to me.**

Elderly Dads and Moms have an uncanny ability to marshal their resources for the occasional visit of the out-of-town or uninvolved child, making the caregiving child's accounts of their behavior seem unreasonable. This statement has many variations: "Dad always got lost and drove too fast"; "Mom never could balance a checkbook"; "I forget things too." Less-involved siblings should make it a point to drop in unannounced and stay for a long enough time to see how Mom or Dad act under everyday circumstances.

## **4 I don't know how you do it. You must be a saint.**

For a caregiver beset with frustration, depression, anxiety, and exhaustion, being told that you're a saint is decidedly unhelpful. (There may be some exceptions among those who aspire to martyrdom.) While this statement is surely meant to express admiration, it has the unintended or perhaps unconsciously intended result of distancing the speaker from the caregiver. After all, how many saints are there in the world? And if the caregiver is one, then the noncaregiver certainly won't be called upon to be one. Instead of sanctification, most caregivers would prefer a little help, which leads me to....

## **3 Just call me if you need some help.**

This is sometimes phrased as "I wish there were something I could do to help." Most caregivers have learned that imprecise, indefinite, offhand offers of help are expressions of good will but little else. The speaker feels better ---"After all, I did offer, and she never called," while the caregiver thinks, "What exactly does she mean by 'help'?" Friends or other family members who really want to help should make specific offers such as, "I'm going to the farmer's market; can I bring you some vegetables?" "I can stay with Mom on Saturday so you can do some shopping or go to a movie." "I know it's hard for you to get out for dinner, so I'd like to bring dinner to you one night this week." These are small things; the list could get progressively more complex and demanding. But whatever the offer, it should be firm and nonrefundable.

*Top 10 Things continued on page 9*



## **2 I know just how you feel.**

This is another attempt at solidarity that fails. The caregiver is probably thinking, “No, you don’t because sometimes I don’t even know myself how I feel.” Caregiving involves a complex and dynamic array of emotions, which each person experiences and internalizes differently. This statement shifts the focus away from the caregiver to the speaker, who frequently follows it up by talking about his or her own caregiving experience.

## **1 God doesn’t give you more than you can handle.**

No. 1 on my list showed up surprisingly frequently on other people’s lists, including members of the clergy, as well. This statement, sometimes phrased as “Don’t worry, God will be good” is intended to be comforting, and for many people it may be. They need read no further. Why then do so many people find it upsetting? For me, the primary reason is that it is demonstrably untrue. Millions of individuals succumb to what God, fate, natural disaster, violence, or political, social, or economic turmoil have wrought. For caregiving specifically, studies have demonstrated that spousal caregivers are at increased risk of dying compared to their noncaregiving peers. And even if they don’t die, their health and well-being are permanently affected. Unlike patient, long-suffering Job in the Bible, caregivers’ losses are not repaid twice over when the challenge match between God and Satan is concluded. (What would I do with 6,000 camels anyway?) As Rabbi Gerald Wolpe, himself a caregiver, points out, Mrs. Job, the caregiver, is disdained and disregarded, and the new children given to Job do not replace those she has lost. From the Christian tradition, Kenneth Doka, a Lutheran minister and gerontologist, says, “Only the caregiver knows the extent to which he or she can bear a particular burden, and such comments could make the caregiver feel inadequate and unworthy.” Rev. Andy Calder, an Australian minister, says: “People hear these statements as clichés of judgement – of God being against them. The recipients are cast as people whose faith is perhaps suspect, as people who have perhaps incurred God’s wrath for some misdeed, and as people who have no control over their circumstances: indeed, as victims.” For me, the most helpful approach comes from Rabbi Harold Kushner, author of *When Bad Things Happen to Good People*, who says: “[Bad things] do not happen for any good reason which would cause us to accept them willingly. But we can give them a meaning.” Prayer, spiritual solace, and religious rituals can help give meaning to caregiving, as can many other responses. Easy answers do not suffice.

So that’s my “how not to” list. And here are a few additional suggestions for the “how to” list.

## **3 I have a friend who is having a lot of difficulty getting started as a caregiver. Would you be willing to talk to her?**

Generally caregivers are very willing to help each other, as long as there are clear boundaries. Giving back what one has learned from painful experience can be gratifying. The decision, of course, depends on timing and mutuality of experiences.

## **2 I haven’t seen you in a while, and I miss our (lunches, shopping, bowling, volunteering, whatever).**

Caregivers are isolated, and phone calls can be welcome invitations to rejoin the world. Ideally, of course, the caller will follow up with a specific plan to meet.

*Top 10 Things continued on page 10*

## 1 How are you doing?

Some people ignore the caregiver altogether, looking the other way so that they do not have to have any conversation at all. Many people will ask about the ill person but not the caregiver. It's appropriate for family and friends to ask about the care recipient but they should be sure to follow it up with concern about the caregiver. And then they should follow the caregiver's lead. Sometimes he or she will want to talk about caregiving, and sometimes about something—anything--completely different. Listening well is the best support one can give, and the best support a caregiver can receive.

*Carol Levine is director of the Families and Health Care Project at the United Hospital Fund in New York City. She is the editor of *Always On Call: When Illness Turns Families into Caregivers*, 2nd edition, Vanderbilt University Press, 2004; and co-editor, with Thomas H. Murray, of *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*, Johns Hopkins University Press, 2004.*

## Reports and Publications

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### Evercare Study Finds Stress, Depression, Fatigue Propel Caregivers Into Downward Health Spiral

According to the *Evercare® Study of Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One*, released in September, the stress and worry of caregiving lead millions of caregivers to neglect their own physical and mental health, resulting in depression, extreme fatigue, poor eating and exercise habits and greater use of medications. More than half (53 percent) surveyed said this downward health spiral also negatively affects their ability to provide care.

#### Extreme stress leads to alarming health symptoms and behavior

An alarming nine in 10 (91 percent) caregivers surveyed — all in fair/poor health and having seen a decline in their health as a result of caregiving — suffer from depression, and eight in 10 (81 percent) of those with depression reported that caregiving has made their depression worse. Respondents cited stress as the most pervasive health problem in their lives, stemming from worry about their loved one's condition as well as being overwhelmed with caregiving responsibilities. In focus groups, caregivers recount how the stress emerges in various physical ailments, including increased blood pressure, heart attack scares, arthritis flare-ups, acid reflux, headaches and other symptoms.

#### Caregivers sacrifice their own health maintenance in favor of their caregiving duties

The Evercare Study also found that, among caregivers surveyed, caregiving often replaces their own health maintenance. Despite being in fair or poor health and worsening health since becoming caregivers, nearly three in four (72 percent) admit they have not gone to the doctor as often as they should, and more than half (55 percent) have missed doctors' appointments. One in five women report having mammograms less often (21 percent) and a similar proportion of men are not as up to date with their prostate exams as they once were (23 percent). Also, 33 percent say they get their teeth cleaned less often, 29 percent neglect periodic vision tests, and 26 percent skip periodic physical exams.

*Caregivers in Decline continued on page 11*

Among the other key findings of the study:

### **Caregivers Feel Alone, Don't Know How to Ask for Help**

Although they often have family members or friends who could help them, they sometimes shoulder more responsibility than they have to because they don't know how to ask for help. Support from family and friends has the potential to relieve their burden, but caregivers must overcome the barrier of not knowing how or when to ask for help. Among those surveyed:

- The large majority (75 percent) feel they had no choice in taking on their caregiving responsibility.
- Nearly seven in ten (69 percent) spend less time with family and friends.
- Half of those surveyed (51 percent) would like to talk to someone who could help them identify tasks that other family members or friends could be doing, and teach them how to gain that cooperation. Respondents think an outside consultant could help them approach their families in a different way, or teach them to delegate and prioritize their tasks better.

### **Caregiving Is a Full-Time Job – Respondents Spend Average of 41 Hours Doing It**

- Thirty-seven percent spend more than 40 hours a week providing care, and 30 percent spend 20-39 hours per week doing so.
- More than one-third of those surveyed (37 percent) report spending less time at their jobs.
- Those who work full-time are more apt than others to say their eating habits are worse than before (73 percent vs. 53 percent for part-timers and 62 percent for those retired or not employed).

### **More Hours Spent Caregiving Equated with Greater Decline**

Previous studies have shown that caregivers spend on average 4.5 years caregiving, with the needs escalating over time, thus impacting caregiver health significantly over that period (*Caregiving in the U.S.*, AARP and National Alliance for Caregiving). The Evercare study revealed that the more time caregivers spend caring for a loved one, the greater their health decline. This is even more true for those caregivers providing a higher level intensity of caregiving such as giving medications or injections, bathing, feeding, dressing or other activities of daily living. Caregivers who reported their health got a *lot* worse as result of caregiving (15%) spend an average of 58 hours a week caregiving and those with a moderate deterioration in health (44 percent) spend an average of 42 hours a week caregiving.

### **Caregivers Describe Support Services They'd Prefer Most**

The caregivers surveyed are receptive to support services that could help them save time, reduce stress, manage their own health more effectively or provide them with caregiving expertise. The majority of respondents say they would be likely (63 percent very/somewhat likely) to call an expert about the stress they feel and other caregiving issues. More than six in ten (63 percent) say they would also use services provided by a mobile health van, and they explain that such a service might make them more likely to take care of their own routine health care. Similarly, half of respondents (50 percent) would like to be able to call a nurse to stay with their loved one while they go to the doctor themselves.

*Caregivers in Decline continued on page 12*

The *Evercare Study* also found that the existence of caregiver support services is not sufficient to ensure that they are used. Caregivers need to be made aware of support services through concerted communications efforts, and may also need encouragement to try whatever services are offered.

Copies of the study may be downloaded from the Alliance's website at [www.caregiving.org](http://www.caregiving.org).

## **CDC & University of Florida Announce Caregiver Module Administration in 4 States**

The Centers for Disease Control and Prevention and the University of Florida are partnering to produce the first-ever population-based surveillance data on family caregiver health. Four states - Hawaii, Kansas, Washington, and Rhode Island - will administer the new Caregiver Module of the Behavioral Risk Factor Surveillance System (BRFSS), the world's largest ongoing telephone health survey system.

The awarded states will include 8 questions specific to caregiving on the 2007 BRFSS to improve understanding of the health effects of caregiving at a population level. These questions will provide information on the relationship between caregivers and care recipients, the time intensity and burden associated with providing care, the areas in which care recipients need help, and the types of difficulties caregivers face. In addition to the eight basic questions, each state may add additional questions to collect information relevant to specific issues within their state.

*Administration of the BRFSS Caregiver Module will build on its successful 2005 pilot test in North Carolina. Elena Andresen, PhD, at the University of Florida, oversees this project, which is funded by CDC and directed by John Crews, DPH, and Ronda Talley, PhD, MPH. Andresen and her team created the module in 2004 with input from national experts and stakeholders. Elena Andresen is supported in part by the North Florida/South Georgia VA Medical Center. For additional information, please contact Erin DeFries at 352-273-5279, [edefries@phhp.ufl.edu](mailto:edefries@phhp.ufl.edu), or Elena Andresen at 352-273-5359, [eandresen@phhp.ufl.edu](mailto:eandresen@phhp.ufl.edu).*

## **Family Caregiving Valued At \$306 Billion Market Value of "Free" Services Jumps 19 Percent in 4 Years; California Caregivers Top Charts**

The value of "free" services provided by family caregivers to their chronically ill, disabled or aged loved ones jumped to \$306 billion--a 19% increase in the past four years--according to research by Peter S. Arno, PhD, a health economist at Montefiore Medical Center/Albert Einstein College of Medicine, Bronx, NY. A State-by-state analysis of the number of family caregivers, hours of caregiving services and their estimated market value was released in November by the Family Caregiver Alliance and the National Family Caregivers Association. The largest caregiving states, according to the new analysis, are California, with an annual market value of over \$36 billion, followed by Texas at \$22 billion; New York at \$20 billion; Florida at \$19 billion; and Pennsylvania at \$13 billion.

State-by-state data are available on the Family Caregiver Alliance website, at [http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1805](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1805). For more information, visit Family Caregiver Alliance at [www.caregiver.org](http://www.caregiver.org) and National Family Caregivers Association at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org).

## Resources

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### Long-Term Care Planning Focus of New HHS Campaign

The Department of Health and Human Services (HHS) launched Phase III of its *Own Your Future* campaign in six states (Georgia, Massachusetts, Michigan, Nebraska, South Dakota, and Texas) this fall. The campaign is part of an ongoing effort to increase awareness about what public programs pay and what Americans should plan to pay themselves for long-term care. Educating the public about available financing options will be critical to help people choose and pay for the long-term care environment, service, and supports that are right for them. Phase I of the campaign was launched in January 2005 and included Arkansas, Idaho, Nevada, New Jersey, and Virginia. Phase II, launched in January 2006, included Kansas, Maryland, Rhode Island, and Washington.

Governors in participating states will send letters to all households with residents between the ages of 45-65 encouraging them to consider their future long-term care needs and to order a free Long-Term Care Planning Kit. The kit features information about planning strategies, legal considerations, private and public financing options, and tools to help make decisions about your care needs. Participating states will also be conducting complementary outreach activities promoting local long-term care resources.

For more information about the *Own Your Future* campaign, contact Hunter McKay, HHS/ASPE at 202-690-6443, [hunter.mckay@hhs.gov](mailto:hunter.mckay@hhs.gov) or visit [www.aoa.gov/ownyourfuture](http://www.aoa.gov/ownyourfuture) on the web. You can order a long-term care planning kit by calling 1-866-PLAN-LTC.

### Medicare Interactive: New Sections for Caregivers

Medicare Interactive has added new sections for family caregivers. The new sections can be accessed from the Topic Index page and contain the following information:

#### Under **Section VIII. Medicare Advice for Caregivers:**

- a. **Caring for a Loved One:** Addresses general questions such as “Will Medicare help me care for my loved one at home?”
- b. **Understanding Your Rights as a Caregiver:** Explains what rights a caregiver has to make health care decisions (both medical and insurance) on behalf of a loved one.
- c. **Information About Your Loved One:** Details what health, financial, and insurance information a caregiver should gather to be the best possible advocate.
- d. **Resources for Caregivers:** Offers advice on where to go for assistance and support.

#### Under **Section V. Medicare Rights and Protections:**

- k. **Getting Quality Care:** Offers advocacy tips on how to best communicate with doctors, hospital staff and insurance representatives to get the best possible care.
- l. **Preparing for Your Future Health Care Needs:** Offers advice on how to make sure you get the health care you want if you can no longer speak for yourself (information on health care proxies, living wills and powers of attorney).

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To view the new sections, log on to Medicare Interactive from the National Alliance for Caregiving's website at [www.caregiving.org/medicare/index.htm](http://www.caregiving.org/medicare/index.htm). This internet resource is provided by the Medicare Rights Center, the largest independent source of health care information and assistance in the United States for people with Medicare.

## Planning and Coordinating Care for People with Alzheimer's Disease

Caregivers and health care professionals are invited to listen to this FREE educational web seminar presented by the Medicare Rights Center, thanks to generous funding provided by the Eisenberg Family Trust. This informative web seminar will provide you with the tools you need to help loved ones and clients in the early stages of Alzheimer's disease. During the presentation, you will learn about:

- Advance Directives: How to designate someone to make health care and financial decisions for you if you cannot.
- Long-Term Care: Planning: coordinating and paying for these services.
- Medicare-covered services: What Medicare covers and your rights and protections as a person with Medicare and Alzheimer's disease.

Go to [www.medicarerights.org/webseminar.html](http://www.medicarerights.org/webseminar.html) to hear the recording.

## New Features in the Online Database, Caregiving Across the States

The National Center on Caregiving at Family Caregiver Alliance (FCA) is pleased to announce the addition of exciting new features to its online resource, *Caregiving Across the States*. This interactive database, accessible in map format on the FCA website, is a valuable resource to inform state administrators and policymakers about support programs for family caregivers of adults with chronic illnesses or disabilities. It also allows caregivers and service providers to access information they need to seek assistance and benefits for themselves or their clients. The database includes a separate profile for each state and the District of Columbia. Profiles contain the state's background characteristics related to caregiving and aging, as well as information on publicly funded caregiver support programs. You'll find the updated data in the "Selected State Background Characteristics" sections of the state profiles. NEW state-by-state data include:

- Where Caregivers Call to Arrange for Help
- Medicaid Spending on Long-Term Care
- Average Assisted Living Monthly Cost
- Median Hourly Wages for Home and Health Care Workers
- Medicare Prescription Drug Plans
- Population Statistics for Adults Age 60+
- State-Specific Caregiver Statistics
- Number of Certified Nursing Facilities
- Percent of Adults (21+) with a Disability

To learn more about the family caregiving landscape in your state, visit FCA's Caregiving Across the States webpage: [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1274](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1274).