

# Study Finds Higher Outlays For Caregivers of Older Relatives

### The Cost of Care

A recent survey looked at the out-of-pocket spending of Americans who care for an adult over 50 needing help with daily activities like bathing, preparing meals, shopping or managing finances. The survey was conducted by telephone in June and July and included 1,000 respondents. Here are some of the survey's findings.

#### Out-of-pocket spending

The average annual spending on care among all survey respondents was more than \$5,500. Here is a breakdown:

Medical	\$1,161
Meals, household goods	868
Travel	551
Home health services	547
Assisted living/nursing home	497
Home maintenance, repairs	447
Housing payments	354
Caregiver support services	343
Home modifications	262
Clothing	241
Medical equipment/supplies	182
Legal fees	78

#### Compensations

The percentage of respondents who compensated for expenses in these ways:

Cut back on spending for hobbies, leisure activities	49%
Cut back on vacations	47
Used savings	34
Deferred major purchase or home improvement	34
Cut back spending on groceries	25
Cut back on own spending for health or dental care	23
Reduced or stopped saving for children's future	18

#### Time providing care

Lower income families spent more time.

Annual income	Average hours of care per week
Less than \$25,000	41
\$25,000-\$50,000	38
\$50,000-\$75,000	36
\$75,000-\$100,000	23
More than \$100,000	23

Source: National Alliance for Caregiving

THE NEW YORK TIMES

By JANE GROSS

**T**he out-of-pocket cost of caring for an aging parent or spouse averages about \$5,500 a year, according to the nation's first in-depth study of such expenses, a sum that is more than double previous estimates and more than the average American household spends annually on health care and entertainment combined.

Family members responsible for ailing loved ones provide not only "hands on" care but often reach into their own pockets to pay for many other expenses of care recipients, including groceries, household goods, drugs, medical co-payments and transportation. That nudges the average cost of providing long-distance care to \$8,728 a year.

These caregivers, spending on average 10 percent of their household income, manage the financial burden by taking out loans, skipping vacations, dipping into savings or ignoring their own health care.

These findings and others, to be released today, came from a telephone sur-

vey of 1,000 adults caring for someone over age 50 who needs help with activities like bathing, using the toilet, preparing meals, shopping or managing finances. It is the first detailed look at out-of-pocket spending among the estimated 34 million Americans providing care for older family members or friends and builds on a 2004 study.

The survey was conducted by the National Alliance for Caregiving, a research and policy organization, and Evercare, a division of the UnitedHealth Group, which coordinates long-term care for 150,000 clients. The report urges government assistance for family caregivers, whether through tax deductions, tax credits or other stipends.

"Typically, when people talk about services for caregivers, they mean respite care, support groups and things like that," said Gail Gibson Hunt, president of the National Alliance for Caregiving. "They don't think of the financial side being tied into the burden. If you're spending 10 percent of your income,

that's part of what's weighing on you, and policymakers haven't paid enough attention to that."

Until now, all estimates of out-of-pocket spending were based on a single question buried in a broad 2004 survey of family caregivers, according to Ms. Hunt and Donna Wagner, a gerontologist at Towson University in Maryland who analyzed the data for the new report.

The 2004 survey, also the work of the National Alliance for Caregiving, had asked 1,247 caregivers to estimate their out-of-pocket expenses. Half said that they did have such expenses, averaging \$2,400 a year.

By comparison, the new survey — with 29 questions devoted to this one subject — produced a markedly different result. Of the 1,000 respondents, only 2 said they had never laid out any money. The rest said they spent on average \$5,531 a year, or 10 percent of their salary. The burden was heavier for those who earned less, 20 percent for respondents with incomes of \$25,000.

Melissa Phillips, 45, a stay-at-home mother in Clayton, Ind., has spent \$6,000 a year since her father moved from his own home into an assisted-living center, largely on groceries, incidental expenses and medical equipment like a wheelchair and a riser for the toilet seat. She helps out a bit with the monthly rent so his savings last longer and will pick up the slack if he runs out of money.

For Mrs. Phillips, a respondent in the survey, her present circumstances are an improvement over the 10 months before her father left his own house, when he was in and out of the hospital. She and her three children moved in with him, disrupting their home schooling, while her husband remained at home.

Costs ran higher then, Mrs. Phillips said, because she paid her father's larger-than-usual utility bills, as well as gasoline and restaurant meals for her own family when she was running back and forth to the hospital.

But since Mrs. Phillips did not have a paying job, she lost no income — unlike the 37 percent of survey respondents who had to quit work or reduce their hours because of their care-giving responsibilities. That compares with 16 percent in the 2004 research.

These are among other findings in the latest survey:

The most common expenses for caregivers are household goods and food (42 percent of respondents), transportation (39 percent), medical co-payments and pharmaceuticals (31 percent), clothing (21 percent), and home repair and maintenance (13 percent).

The most common strategy for covering these costs is cutting back on discretionary spending. Respondents reduced spending on leisure activities (49 percent) and vacations (47 percent), and postponed major purchases or home improvements (34 percent).

Other strategies involve caregivers compromising their own retirement. Some dipped into savings (34 percent);

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## *The first detailed look at a financial burden borne by millions.*

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others limited saving for the future (27 percent). And many neglected personal health care (23 percent).

The highest out-of-pocket costs were incurred by long-distance caregivers, followed by those who live with their ailing relative. Caregivers who live nearby spend the least.

In addition to the telephone part of the survey, the report also includes detailed information and narrative accounts from 41 men and women who were paid \$100 to keep expense diaries over the course of a month. This subgroup — not a representative sample because they were self-selected and were paid — reported sharply higher expenses than the telephone respondents.

The diarists spent an average of \$12,348 a year — more than double the annual expenses of the larger, randomly selected

telephone sample. In addition, the diarists who lived with their older relatives, spent the most — \$14,832 a year, followed by \$14,064 for long-distance caregivers and \$8,496 for those who lived nearby.

These discrepancies are not explained in the study, entitled "Family Caregivers: What They Spend, What They Sacrifice." But both Ms. Hunt and Ms. Wagner speculated that the diarists' situations were atypically complex or that day-to-day record-keeping produced more accurate information than did recollection.

Each diarist was assigned a researcher, who checked in regularly by phone or by e-mail. All the researchers found themselves consoling caregivers who welcomed their calls, Ms. Wagner said: "Having us care about their life was big plus."

That was the case for Bill Camarata, 48, who has been living with his 77-year-old mother outside Cleveland since 2002 because of her dementia. Mr. Camarata's out-of-pocket expenses are a low \$2,400 a year because his mother has enough money to pay for most of her needs.

But he said in a telephone interview that he was drained by the responsibility, especially since he also worked a full-time job. He said he also was dispirited by marriage plans that have been indefinitely postponed.

Why did he agree to the extra chore of keeping the diary? And what did he get out of the experience other than \$100?

"It's the emotional part that's so hard, so it was nice to get positive feedback," Mr. Camarata said. "You never get enough reassurance that what you're doing is right."

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