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Caregiver Survey

November 2012

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Caregivers – adults who provide unpaid care to older people and adults with disabilities – are often overlooked and underappreciated in American society. In 2011, a study from MetLife¹ estimated that 10 million Americans over the age of 50 were caring for aging parents. The National Alliance for Caregiving and AARP estimate² that about 44 million Americans between the ages of 18 and 65 – more than twenty percent (20%) of the U.S. population — provide unpaid care to older people and adults with disabilities. In 2009, the National Family Caregivers Association and the Family Caregiver Alliance valued the amount of unpaid labor these caregivers provide in the state of California alone at over \$30 billion per year³.

In August 2012, PlanPrescriber.com partnered with AgingCare.com to survey 285 adult members of AgingCare.com who were actively providing unpaid care for one or more of their parents. The survey provides insight into the emotional and financial challenges that caregivers face on a daily basis, as well as their understanding and utilization of Medicare.

About the Caregivers in the Survey

	All	Female	Male
Gender		89%	11%
Age			
• 18-25	1%	1%	0%
• 26 - 35	5%	5%	0%
• 36 - 45	11%	11%	11%
• 46 - 55	39%	37%	50%
• 56 - 64	35%	36%	29%
• 65+	10%	10%	11%
Married	53%	53%	53%
Single	24%	24%	32%
Divorced	18%	18%	14%
Widowed	5%	6%	0%
Also caring for one or more children under the age of 18?	17%	17%	19%
Where they're from (43 states and DC)			
CA		12%	
FL		10%	
NY		7%	
PA		7%	
VA		4%	
35 other states and DC		53%	

Being a Caregiver: The Emotional Impact

Caring for an older parent is often rewarding, but it's not without its challenges. Being a caregiver can be difficult, time consuming and costly, which can make it difficult to view one's role as a caregiver in a positive way.

In the survey, caregivers were asked about the positive and negative aspects of being a caregiver. They were also asked how their role as a caregiver impacted their relationships with family, friends and coworkers.

How do caregivers feel about their experience?

The survey asked caregivers to qualify the emotional impact of being a caregiver in one of three ways: mostly positive, mostly negative or equally positive and negative. A high percentage said the experience was mostly negative.

- **33% - Mostly negative.** One-third of those surveyed said their experience as a caregiver had a mostly negative impact on their lives.
- **9% - Mostly positive.** By comparison, less than one-in-ten of those surveyed said their experience as a caregiver had a mostly positive impact on their lives.
- **58% - Equally positive and negative.** The majority felt being a caregiver had made an equally positive and negative impact on their lives.

How does being a caregiver impact one's relationships with the care receiver?

Taking care of a parent can also impact the caregiver's relationship with the parent they're caring for.

- **25% - Negative impact.** Twenty-five percent of the caregivers in the survey said that being a caregiver had negatively impacted their relationship with their parent(s).
- **32% - Positive impact.** Nearly a third said it had improved their relationship with their parent(s).
- **43% - Little to no impact.** Less than half said it had little to no impact on their relationship; one in 10 (9%) said there was no impact; and one-in-three said it had a minor impact.

Which personal relationships are affected as a result of being a caregiver?

The majority of caregivers (90%) said their roles as caregivers have impacted one or more of their personal relationships. Only one-in-ten (10%) said their relationships with family and friends were not impacted at all. When asked to name all personal relationships that had been impacted, caregivers said:

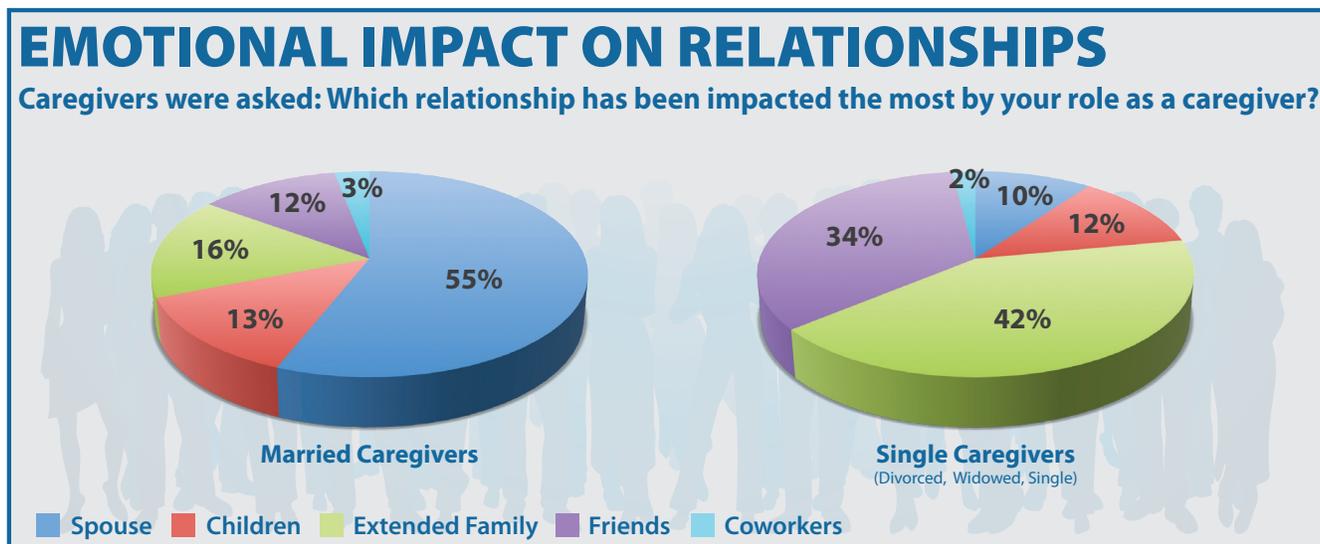
- **58% - Family.** The majority said their relationships with siblings and other family members were altered as a result of caring for their parent.
- **50% - Friends.** Half of the caregivers surveyed said their relationships with friends were affected.
- **22% - Workplace.** About one-in-five said caregiving impacted their relationships in the workplace.

Among married caregivers, the personal relationships that had been impacted included:

- **74% - Spouse.** Three-fourths said being a caregiver impacted their marriage.
- **52% - Family.** Half said being a caregiver had impacted their relationship with family members.
- **48% - Children.** About half said being a caregiver had impacted their relationship with their children.
- **19% - Workplace.** One-in-five said being a caregiver had impacted their relationships in the workplace.

Which relationship has been impacted the most by your role as a caregiver?

More than half (53%) of caregivers are married, and among married caregivers, more than half (55%) said their marriage was most impacted. Single, divorced and widowed caregivers said the relationships most directly affected were those with extended families, children and friends, in that order.



Being a Caregiver: The Financial Impact

As noted in the research from the National Family Caregivers Association and the Family Caregiver Alliance, many caregivers provide financial support to aging parents, in addition to providing physical and emotional care.

In 2009, the average income for people ages 65 and over was \$29,718,⁴ according to the U.S. Census Bureau's 2010 Current Population Survey. In 2008, sixty-nine percent (69%) of seniors on Social Security received more than half of their income from Social Security. For one in four seniors, Social Security was their only source of income.

Many Americans are behind when it comes to saving for retirement, and caregivers are no exception. Experts encourage people to have three times their annual salary saved by age 45, and eight times their annual salary saved by the time they retire. The majority of caregivers in this survey (84%) were over the age of 45. In May 2012, Fidelity Investments reported⁵ that their average customer had \$72,800 in their 401K retirement savings account, and that less than half (45%) of their average customers were on track to reach their retirement goals. By comparison, most caregivers (65%) say they're not saving enough for retirement.

The financial obligations of caregivers

The PlanPrescriber/AgingCare survey found that the majority of all caregivers (60%) were "completely involved" in helping their parents make personal finance and retirement decisions. Only fourteen percent (14%) were not involved in their parents' finances at all.

In addition, two-fifths (41%) were helping their parents financially each month. Among those, half (49%) spent \$3,000 or more per year to support their parents financially. One-in-four (24%) spent over \$6,000 per year on their parents' care.

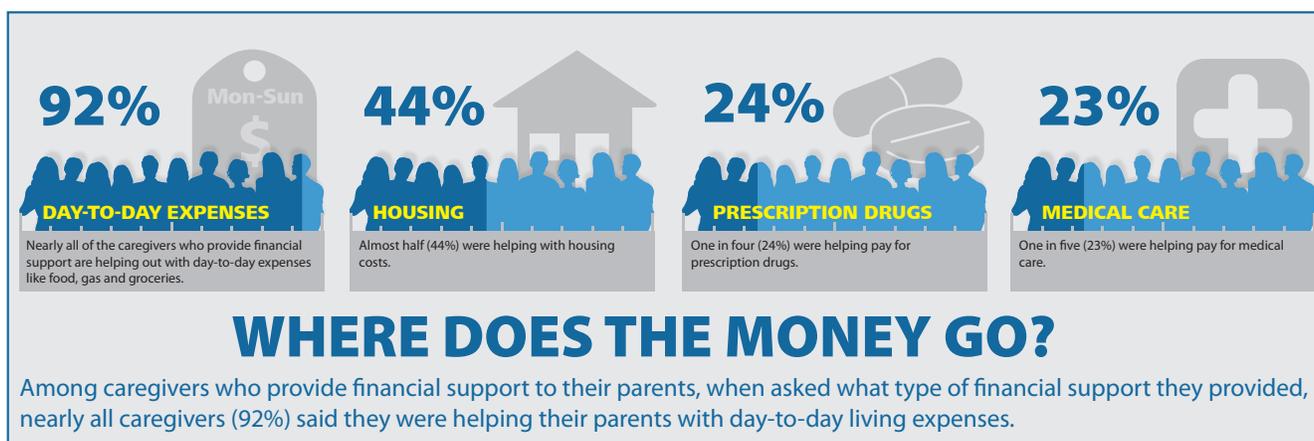
How much financial support do you provide to your parents?

Amount per month	Caregivers providing financial support	All caregivers
\$500 or more	24%	10%
\$250 to \$499	24%	10%
\$100 to \$249	27%	11%
\$50 to \$99	20%	8%
\$50 or less	6%	2%
no financial help	0%	59%

Where does the money go?

Among caregivers who provide financial support to their parents, when asked what type of financial support they provided, nearly all caregivers (92%) said they were helping their parents with day-to-day living expenses.

- **92% - Day-to-day expenses.** Nearly all of the caregivers who provide financial support are helping out with day-to-day expenses like food, gas and groceries.
- **44% - Housing.** Almost half were helping with housing costs.
- **24% - Prescription drugs.** One in four were helping pay for prescription drugs.
- **23% - Medical care.** One in five were helping pay for medical care.



Retirement and savings

When it comes to planning for retirement, two-in-five caregivers (43%) felt their parents had not saved enough money for retirement. The majority (65%) felt they were in the same boat as their parents and were not saving enough for their own retirement. And nearly one-third (31%) felt they would have to dip into their own retirement savings to help their parents retire.

Have your parents saved enough for retirement?	Have you saved enough for your own retirement?	Will you have to spend some of your own retirement savings to help your parents?
<ul style="list-style-type: none">• 43% - No• 42% - Yes• 16% – Don't know	<ul style="list-style-type: none">• 65% - No• 21% - Yes• 14% – Not yet saving for retirement	<ul style="list-style-type: none">• 69% - No• 31% - Yes

Caregivers and retirement income from Social Security

When the caregivers in the survey were asked how much they thought they would need to save in order to retire comfortably, nearly half (46%) said they'd need five hundred thousand dollars (\$500,000) or more, the equivalent of eight times a \$62,000 annual salary. Not surprisingly, four out of five (80%) said they expected to be working well after they turn 65.

- 17% - Want to keep working after age 65.
- 62% - Will have to keep working after age 65.
- 31% - Expect Social Security to be 40% or more of their retirement income.
- 14% - Expect Social Security to be 80% or more of their retirement income.

Being a Caregiver: Understanding Medicare

As of Jan. 1, 2011, one baby boomer (a person born between 1946 and 1964) began turning 65 and qualifying for Medicare every eight seconds. A record 2.8 million people qualified in 2011, and that number will rise to 4.2 million per year by 2030. In all, the government says 76 million boomers will age into Medicare, increasing the number of people in the program from 47 million in 2011 to 80 million by 2030.

The majority of the caregivers (84%) in this survey were baby boomers, and most (89%) said the person they were caring for was on Medicare. Although most of the caregivers had parents on Medicare, a large percentage believed several common myths about Medicare:

- **Myth #1: All plans cover the same prescription drugs at the same price.** Nearly half of respondents (45%) incorrectly thought this statement was true.
- **Fact #1: Prescription drug prices vary from plan to plan.** Each Medicare prescription drug plan has a formulary, a list of drugs the plan will and will not cover. Each plan also has a specific, and often different, price it will charge for covered drugs and drugs that are not covered.
- **Myth #2: Medicare covers everything.** More than one-in-four (27%) didn't know this was false.
- **Fact #2: Medicare has gaps.** Parts A and B do not cover prescription drugs. Most services have co-pays, coinsurance or deductibles; and there is no cap or limit on your out-of-pocket costs.
- **Myth #3: Medicare is free.** More than one-in-four (28 %) mistakenly thought this was true.
- **Fact #3: Medicare is not free.** Most people pay a monthly fee for Part B. Some also pay for Part A. All private supplemental Medicare insurance plans (Medicare Advantage, Medicare Supplement plans and stand-alone Part D drug plans) cost money.

Enrolling in Medicare

Among the eighty-nine percent (89%) of caregivers with parents on Medicare, about half (51%) helped their parents review, select or enroll in private Medicare coverage. Among those who help their parents with Medicare, about half (53%) sought help from an outside party.

Among those who sought help:

- 12% - Got help from a licensed agent.
- 17% - Got help from Medicare directly.
- 13% - Used a comparison shopping website.
- 11% - Got help from a friend or local advisor.

What was the biggest surprise you encountered when trying to enroll in Medicare?

In the survey, caregivers were asked to explain what part of enrolling in Medicare they found to be the most surprising or challenging. For most, the biggest surprise was how long it took them to complete the process (26%), followed closely by the complexity of the Medicare program itself (25%):

- 26% - The time it took to enroll.
- 25% - The complexity of Medicare.
- 22% - The cost of supplemental Medicare coverage.
- 16% - Thought the process was easy.
- 13% - Selecting the optimal prescription drug plan.

Combined, the complexity of Medicare and the time it took to enroll in a plan comprised the majority (51 %) of surprises people encountered when helping a loved one enroll in Medicare. The costs associated with Medicare ranked as the biggest surprise for about one-in-five (22%) of caregivers. About one-in-eight (13%) said selecting the right drug plan was the most challenging activity.

Biggest surprises while enrolling in Medicare

	All	Worked with an agent	Called Medicare	Used a website	Talked to a friend or advisor
The costs	22%	27%	25%	13%	15%
Complexity of Medicare	25%	33%	45%	6%	8%
The time	26%	13%	10%	44%	23%
Selecting the right drug plan	13%	7%	5%	18%	39%
None	16%	20%	15%	19%	15%

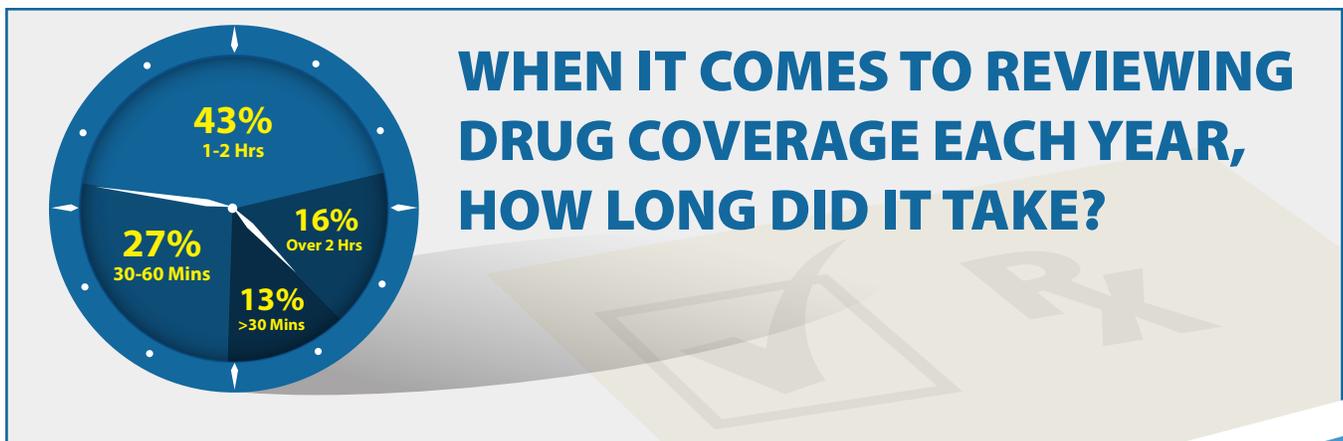
Reviewing Medicare prescription drug coverage

The average Medicare beneficiary with a Medicare prescription drug plan will spend \$2,076 out of their own pocket in 2012, according to PlanPrescriber's 2012 Choice and Impact Study⁴. The study also found that the average Medicare beneficiary could save over \$600 per year, on average, by reviewing their coverage during Medicare's annual enrollment period.

Nearly all caregivers (84%) said they would review their parents' prescription drug coverage if it meant they could save them \$500 or more per year on prescription drug costs. But, only about a third (37%) of the caregivers in the survey said they actually review their parents' prescription drug coverage each year during Medicare's annual enrollment period.

Do you or the person you care for review yours/their Medicare prescription drug coverage each year?

- **51% - No.** We stick with the plan we have.
- **37% - Yes.** We look and will make a change if it means significant savings.
- **12% - I don't know.**



Footnotes

¹ MetLife (<https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Highlights/mmi-caregiving-costs-working-caregivers.pdf>)

² National Alliance for Caregiving (<http://www.caregiving.org/data/FINALRegularExSum50plus.pdf>)

³ A Portrait of Family Caregiving <http://www.thefamilycaregiver.org/pdfs/Portrait.pdf>
U.S. Census Bureau's Current Population Survey, 2010 Annual Social and Economic Supplement (http://www.census.gov/hhes/www/cpstables/032010/perinc/new08_064.htm)

⁴ Congressional Research Service (<http://aging.senate.gov/crs/aging24.pdf>).

⁵ <http://www.fidelity.com/inside-fidelity/employer-services/q2-2012-401k-update>
<http://www.reuters.com/article/2012/09/21/us-column-save-retirement-idUSBRE88K0NB20120921>

⁶ eHealth Study: 95 Percent of Medicare Part D Beneficiaries Not in Lowest-Cost Prescription Drug Plan (<http://news.ehealthinsurance.com/pr/ehi/ehealth-study-95-percent-of-medicare-238719.aspx>)

Other resources: [Strengthforcaring.com](http://www.strengthforcaring.com)
(<http://www.strengthforcaring.com/util/press/facts/facts-at-a-glance.html>)

Media Contacts

For information, analysis, or commentary on this report, please contact eHealthInsurance Media and Government Relations

Media Inquiries:

Brian Mast, Vice President of Communications
(650) 210-3149
brian.mast@ehealth.com

Nate Purpura, Director of PR and Communications
(650) 210-3115
nate.purpura@ehealth.com

Government or Public Policy Inquiries:

John Desser, Vice President of Public Policy and Government Affairs
(202) 626-8573