A decorative graphic is present on the page. It features a large, thin, light-colored arc that starts near the top right and curves down towards the bottom right. A horizontal line and a vertical line intersect at the end of this arc in the bottom right quadrant. A small yellow square is placed at the intersection of these lines. In the top left corner, there is a solid green rectangular area with a small yellow square at its bottom right corner. A thin grey line extends from this yellow square towards the center of the page.

Caregiving and End of Life Issues: A Survey of AARP Members in Florida

February 2009



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Report Prepared by Terri Guengerich

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AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce *AARP The Magazine*, the definitive voice for 50+ Americans and the world's largest-circulation magazine with over **34.5** million readers; *AARP Bulletin*, the go-to news source for AARP's **40** million members and Americans 50+; *AARP Segunda Juventud*, the only bilingual U.S. publication dedicated exclusively to the 50+ Hispanic community; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

Florida Hospices and Palliative Care (FHPC) is a not-for-profit, IRS Section 501(c)(3) organization representing all 41 of Florida's hospice programs. During 2008, Florida hospice programs served over 100,000 patients, and in doing so, touched the lives of over 1 million people. The mission of FHPC is to assure excellence and access to hospice care, and advocate for the needs of those in the final phases of life. FHPC fulfills this mission through the efforts of three "Initiatives". The Excellence Initiative oversees a wide variety of educational opportunities for members of the hospice interdisciplinary teams, as well as, technical and business managers. This initiative works to assure that hospice care in Florida is of the highest quality by offering a variety of programs. It also directs a Consumer Hotline to serve patients, caregivers, and the general public who need assistance or seek hospice information. The Access Initiative works to: remove barriers that could impede access to hospice care; expand the understanding of the end-of-life needs of Florida's diverse population; meet the end-of-life needs of our Veterans; offering information and education to the general public about the availability of hospice care; and raise awareness of the importance of planning for the end-of-life. This initiative is engaged in the commissioning and gathering of a wide array of research projects to support hospice programs in meeting patient, caregiver, and community needs, and for public policy purposes. The Public Policy Initiative educates policy makers in both the legislative and executive branches of government so that decisions made are in the best interest of end-of-life patients and to assure that hospice care in Florida remains the highest quality and most accessible in the United States. The FHPC website is www.floridahospices.org.

The Hospice of the Florida Suncoast, one of the largest and most innovative hospices in the country, offers a broad range of services for the Pinellas County, Florida community including: 24/7 care and support for people living with illness, grief counseling, child and family services, caregiver education, palliative care, AIDS & HIV services, advance care planning, and alternative healing arts such as massage, Reiki, music and pet therapies. As a leader in its field, The Hospice also helps to educate policymakers on a national, state and local level. Founded by volunteers in 1977, this community-based and mission-driven organization maintains the delicate balance between a caring sanctuary and a fiscally sound business through wise stewardship of community resources, making it possible for over 1,500 staff and 3,000 volunteers to provide spiritual, emotional and medical support to more than 2,600 patients every day - regardless of their ability to pay. To learn more about The Hospice of the Florida Suncoast, call (727) 586-4432 or visit www.thehospice.org.

We also express our gratitude to Richard Payne, M.D., Director of the Duke Institute on Care at the End of Life for sharing the Missoula Demonstration Project Community Survey which this survey was loosely based upon.

Acknowledgements

This study is the result of a partnership between AARP Florida, The Hospice of the Florida Suncoast, and Florida Hospices & Palliative Care. Special thanks for their leadership and vision are extended to Kathleen T. Jacobs, Director, Center for Community, and Dr. Joseph Polubinski, Director of Finance-Business Development of The Hospice of Florida Suncoast; Paul A. Ledford, Executive Director of Florida Hospices & Palliative Care; and Scott Melton, Associate State Director of Community Outreach of AARP Florida.

AARP staff from Knowledge Management contributed to this study. Special thanks go to Rachelle Cummins, Erica Dinger, Kate Bridges, Darlene Matthews, and Cheryl Barnes. Don McLennan of FGI, Inc. managed data entry and tabulation of the final survey results. Terri Guengerich of Knowledge Management wrote this report. For more information, contact Terri at (202) 434-6306. The views expressed in this report are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

Survey Highlights

In May 2008, AARP Florida, in partnership with The Hospice of the Florida Suncoast and Florida Hospice & Palliative Care, commissioned a mail survey of a random sample of 8,000 Florida AARP members. A total of 3,024 completed surveys were returned yielding a response rate of 38 percent.

- ▶ Thirteen percent or about 1 in 8 AARP members in Florida say they are providing unpaid care for a relative, friend, spouse, companion, or partner. That's an estimated 395,156 caregivers.
- ▶ These caregivers have provided care for a long time – a third has been providing care for at least six years. Most have been providing care for 1-5 years, and one in eight has been providing care for less than one year.
- ▶ These caregivers say they need help finding information about available caregiving resources in their community, assistance with providing transportation, and help finding accurate medical information.
- ▶ If AARP members could choose where to die, most would choose home. Nearly six in ten members (58%) would choose to die at home if they were terminally ill.
- ▶ When AARP members think of death and dying, they are most concerned about being a burden to others and that their money or their family's money won't last.
- ▶ AARP members are very familiar with Hospice services. Nine in ten have heard about Hospice services. Of these members, eight in ten say their overall opinion about Hospice is extremely or very favorable.
- ▶ Nearly two in three members say they have talked with someone about their wishes for care at the end of their life (64%), most likely their spouse, partner, or other family member.
- ▶ More than half of members say they have created a Last Will and Testament and a Living Will.

Background

Florida has long been recognized as a state where people come to retire, perhaps to escape harsh climates or to enjoy its beaches and recreational activities. Consequently, Florida has the highest proportion of people age 65 and older than any other state. Nearly one in five people in Florida were age 65 or older in 2000 (18%), and this percentage is projected to grow to 27 percent by 2030. This means that the number of people age 65 and older will more than double in this time period.¹

The AARP Florida State Office in partnership with The Hospice of the Florida Suncoast and Florida Hospices & Palliative Care designed this research project to help understand the thoughts, experiences, and attitudes of AARP members in Florida regarding caregiving and end-of-life issues. A mail survey, fielded May 16th through June 27th, 2008, was sent to 8,000 members age 50 and older in Florida. A total of 3,024 AARP members responded, which yielded a response rate of 38 percent and a sampling error of ± 1.8 percent.

To better understand how the experiences of people caring for others and how they deal with end-of-life issues both privately and within their communities, this survey explores AARP members’:

- ▶ Experiences in providing care
- ▶ Thoughts about the end of life
- ▶ Attitudes, opinions, and awareness about Hospice services
- ▶ Planning and decision-making for end-of-life care
- ▶ Involvement in end-of-life issues

The survey was developed in collaboration with the AARP Florida State Office, AARP Knowledge Management, The Hospice of the Florida Suncoast, and Florida Hospices & Palliative Care. The survey is loosely based on the Missoula Demonstration Project Community Survey, an effort aimed at studying the experience of dying and quality at the end of life in the community of Missoula, Montana. The survey was tailored to end-of-life issues in Florida and added many questions on caregiving.

¹ Table 3: Interim Projections: Ranking of States by Projected Percent of Population Age 16 and Older: 2000, 2010, and 2030. U.S. Census Bureau, Population Division, Interim State Populations, 2005.

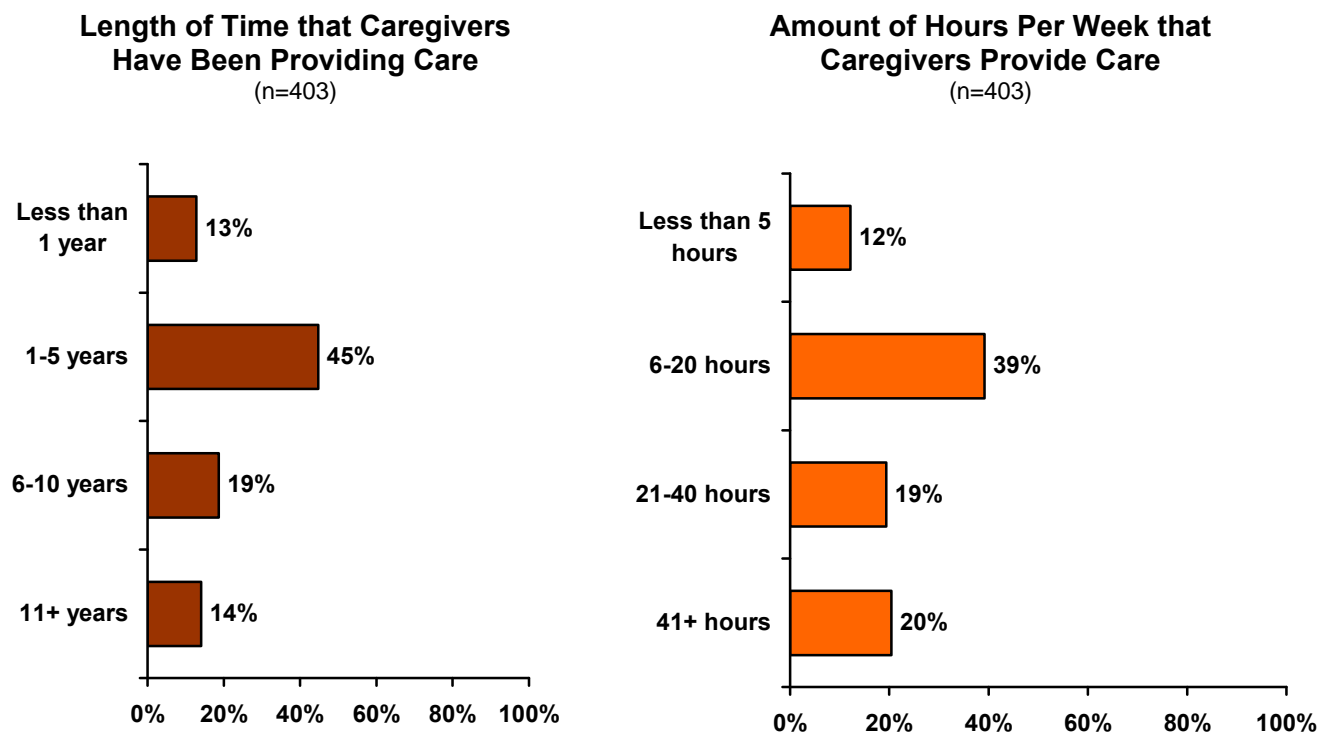
Detailed Findings

AARP Caregivers in Florida

Thirteen percent, or about 1 in 8 AARP members in Florida, say they are providing unpaid care for a relative, friend, spouse, companion, or partner. That's an estimated 395,156 caregivers.

AARP members who are caregivers are more likely to be younger (under 65), female, and married. While most caregivers describe their own health as excellent, very good, or good, one in six describe it as only fair or poor. Half of caregivers say they care for one person; however, 13 percent care for more than one person. Half of caregivers also say that they provide care to someone who lives with them. For those caregivers who travel to provide care, most (47%) travel fifteen minutes or less, and are traveling to the home of the person they care for or to an assisted living facility.

AARP members have been caregivers for a long time – a third has been providing care for at least six years. Most have been providing care for 1-5 years, but one in eight has been providing care for less than one year.



AARP members are spending a lot of time providing care. One in five is spending as much time caregiving as working a full- or part-time job (between 21 and 40 hours a week), and another one in five is spending more time providing care than working a full-time job (41 hours or more a week).

Less than one in five caregivers says that providing care is physically or financially stressful for them. However, two in five say it is emotionally stressful. In fact, emotional stress is more likely to affect younger caregivers (under 60, 56%), female caregivers (46%), and employed caregivers (47%).

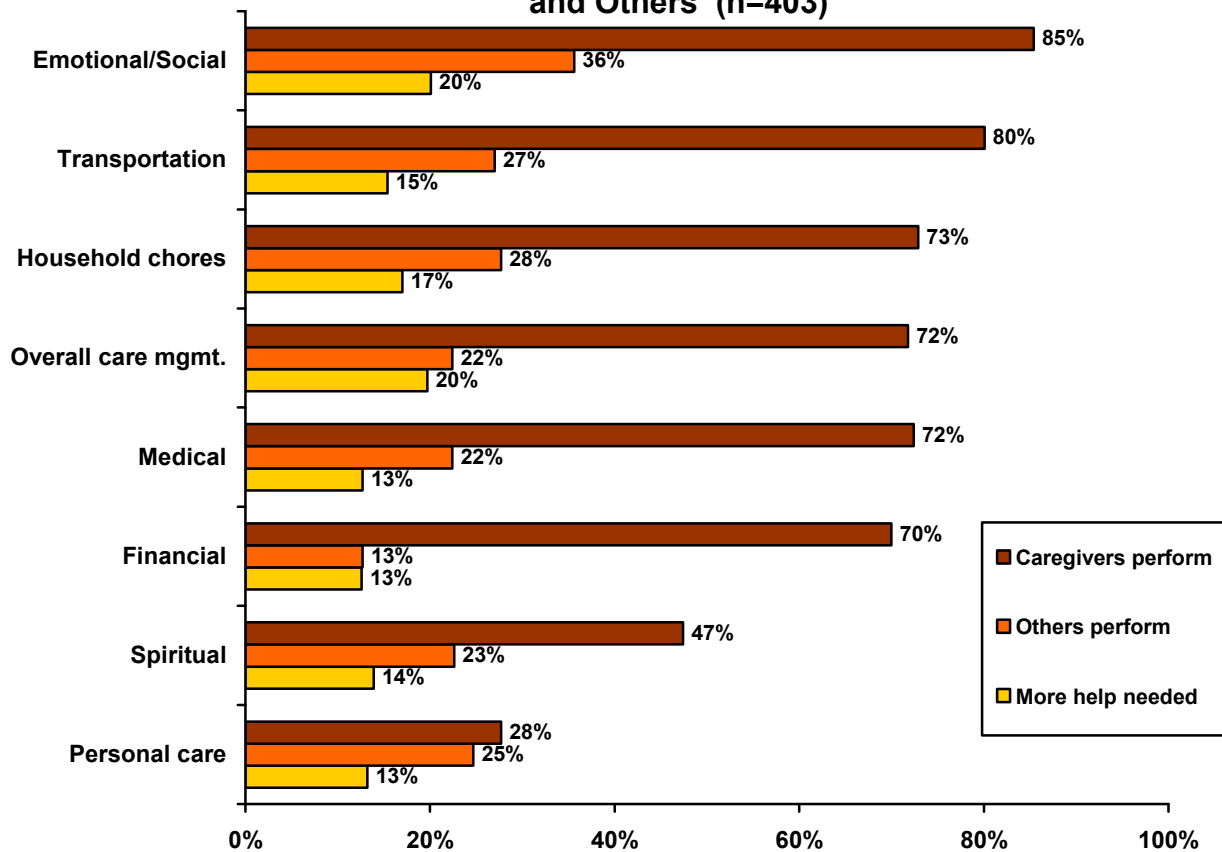
How Stressful Is Providing Care?*

Physically	17%
Financially	19%
Emotionally	39%

*Percent sums extremely and very stressful responses (n=403)

Not only are AARP caregivers spending lots of time providing care, they are providing a wide variety of care. The most common type of support provided is emotional or companionship. Eight in ten caregivers are providing transportation to appointments or running errands. Over seven in ten are helping with household chores, like grocery shopping and cleaning; the overall management of care, including finding services and making decisions about living arrangements and insurance benefits; and helping with their medical needs, like scheduling doctor’s appointments and giving medicine.

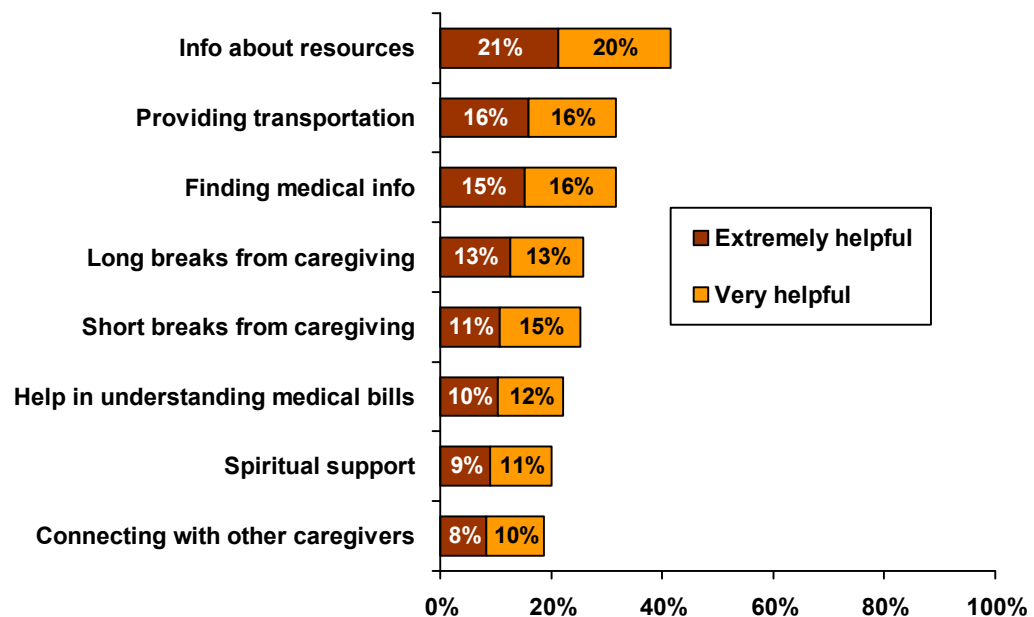
Types of Support or Care Given by AARP Caregivers and Others (n=403)



Exactly seven in ten are also helping with finances, like budgeting and paying bills. About three in ten are helping with daily care such as bathing, dressing, and feeding. One in five caregivers have identified that the person they care for needs more help in the areas of emotional and social support and overall care management.

When asked what types of support would be helpful to them, four in ten caregivers say information about available caregiving resources would be extremely or very helpful, and about three in ten say transportation assistance and finding accurate medical information would also be extremely or very helpful. One in four caregivers would find it helpful to have time off from their caregiving tasks whether it is a long break (a day or so) or a short break (a few hours).

**Helpfulness of Various Types of Caregiving Support
(n=403)**



The act of caregiving may be one way in which AARP members learn about end-of-life issues – learning through their experiences of caring for someone else. AARP caregivers are generally more knowledgeable about advance care directives and other aspects of planning for care at the end of life than AARP members currently not involved in caregiving. AARP caregivers are more likely than non-caregivers to have designated a Health Care Surrogate for themselves (55%, AARP caregivers; 47%, non-AARP caregivers). They are also more likely to have completed a Living Will (59%, AARP caregivers; 53%, non-AARP caregivers) and to report that they have talked with someone about their wishes for care at the end of their life (74%, AARP caregivers; 63% non-AARP caregivers).

Thoughts About End of Life

If AARP members could choose where to die, most would choose home.

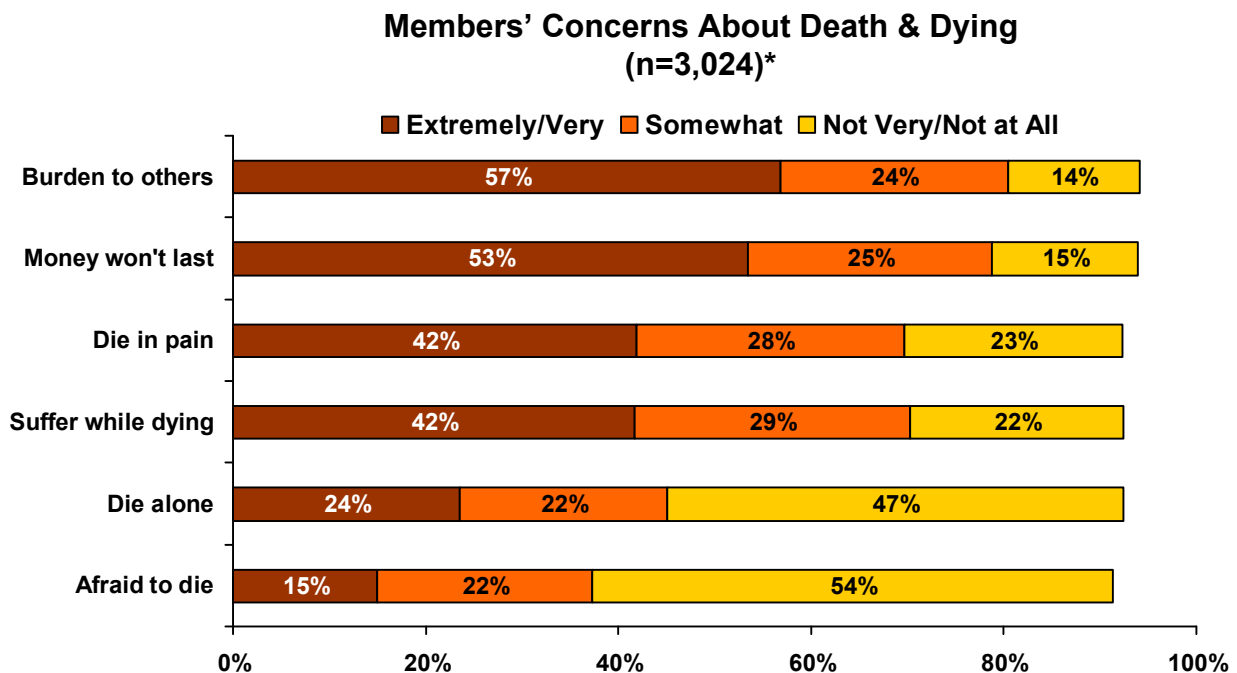
Nearly six in ten members (58%) would choose to die at home if they were terminally ill. Younger members are even more likely to want to die at home (under 60, 67%). Members who identified their health as excellent or very good were also more likely to choose to die at home (62%, excellent and very good health; 56%, good health; 56%, fair or poor health). Members with higher incomes are also more likely to want to die at home (63%, \$50,000+; 52%, under \$20,000). Perhaps as health and income declines, dying well at home may be viewed less optimistically. There may be opportunities here for Hospice to assure people that dying well at home is within reach for everyone.

Fifteen percent of members would choose to die in a Hospice residence, and twelve percent say they have no preference where they would choose to die. Less than five percent would choose to die in a hospital (4%), assisted living facility (1%), or a nursing home (1%).

When AARP members think about death and dying, they are most concerned about being a burden to others and that their money or their family's money won't last.

Younger members (under 65) and members with less income (under \$50,000) are more concerned (extremely and very) about these two outcomes.

About four in ten are extremely or very concerned about dying in pain or suffering while dying. Members are least concerned about dying alone or being afraid to die.



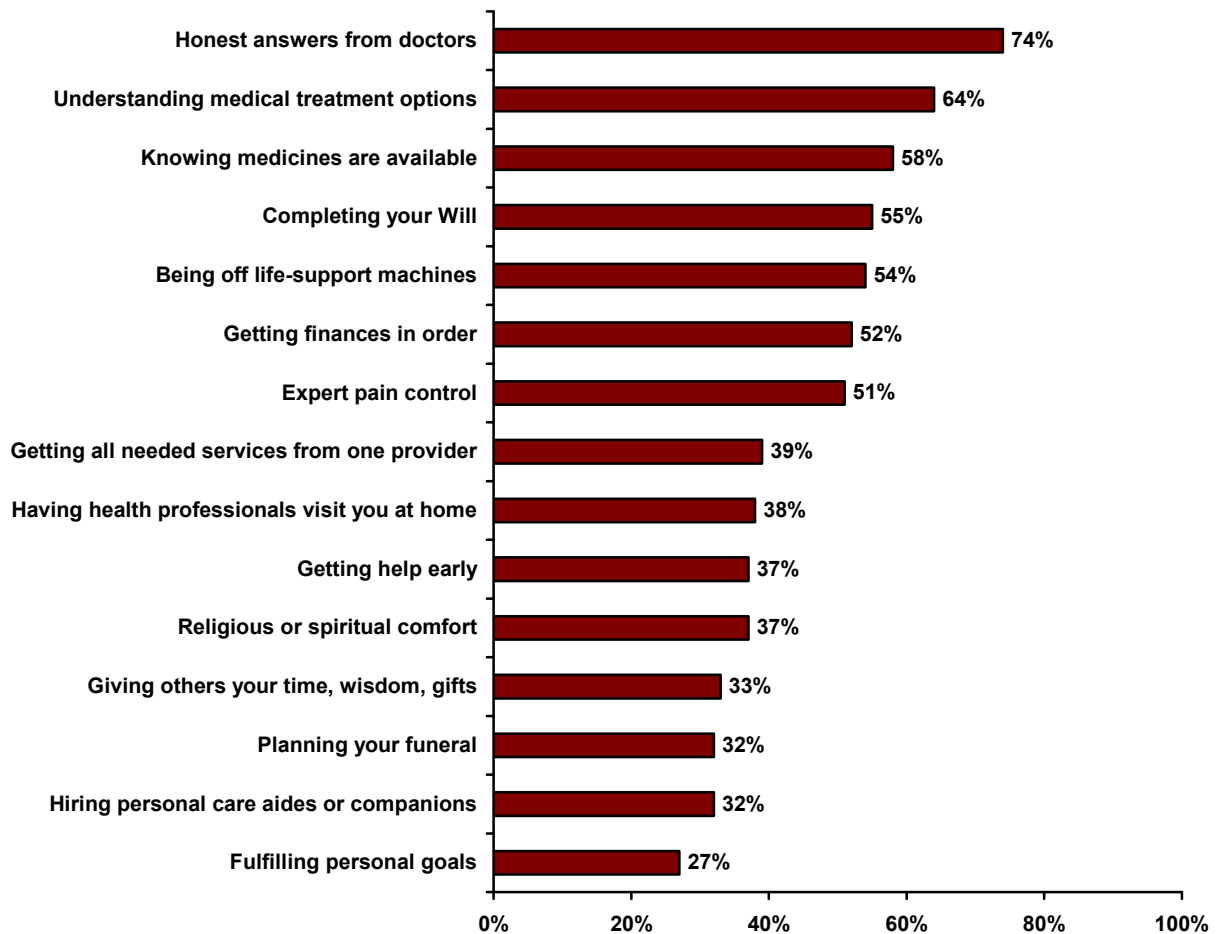
*Excludes missing or no response

Given that most members are concerned about financial issues, it is surprising that the majority of members did not know that Medicare pays for Hospice care. Only three in ten (31%) members who had heard about Hospice knew that Medicare paid for Hospice services. And even more surprising is that only one in three (34%) members with Medicare as their health insurance coverage knew that Medicare paid for Hospice services. There may be opportunities here for Hospice to educate people that Medicare is the primary method of payment for Hospice services.

Getting honest answers from doctors and understanding medical treatment options are extremely important to AARP members in dealing with their own dying.

Also of extreme importance to at least half of AARP members is knowing what medicines are available, finalizing your Will, being off life-support machines, getting finances in order, and receiving expert pain control services.

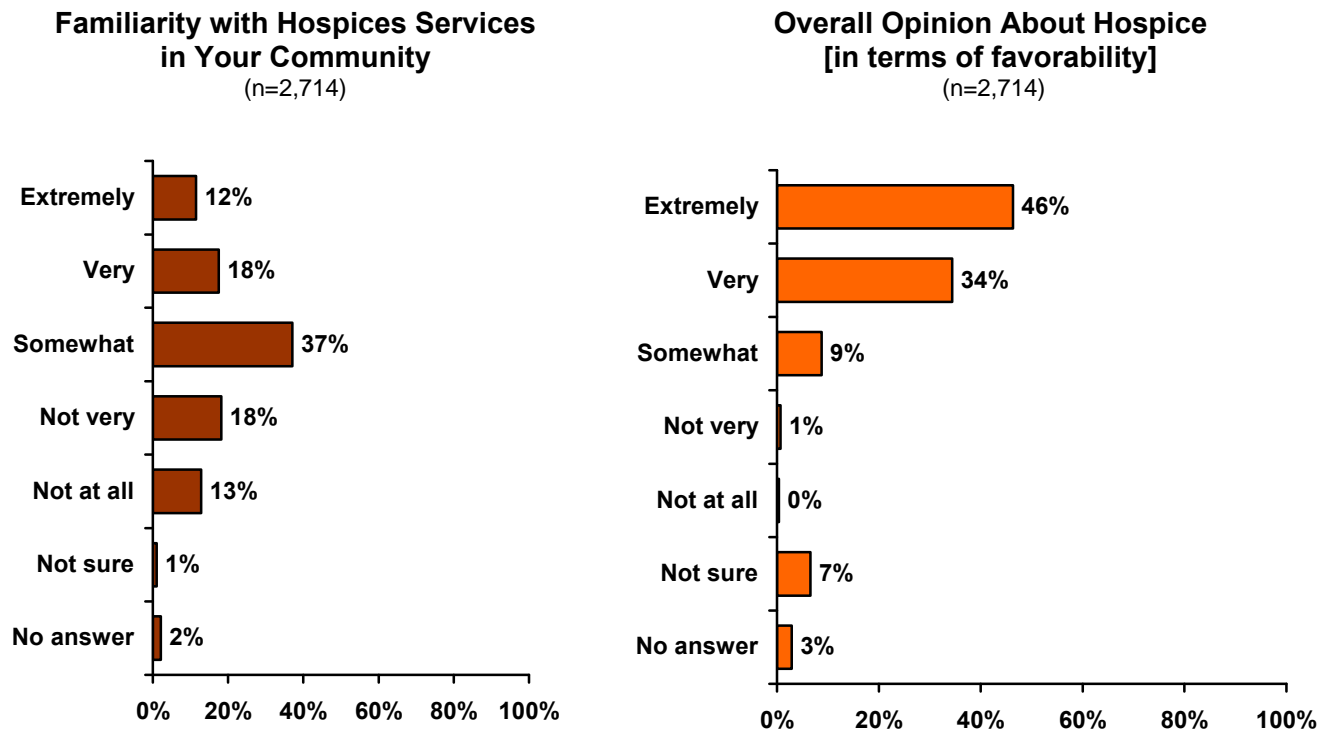
Factors of Extreme Importance to AARP Members When Dealing with Dying (n=3,024)



Hospice Services

Nine in ten AARP members have heard about Hospice services. Of these members, eight in ten say their overall opinion about Hospice is extremely or very favorable.

While AARP members know what Hospice is and have high regard for it, they are as likely to be familiar with Hospice services in their community as unfamiliar with them. Thirty percent of members say they are extremely or very familiar, and thirty-one percent say they are not very or not at all familiar.



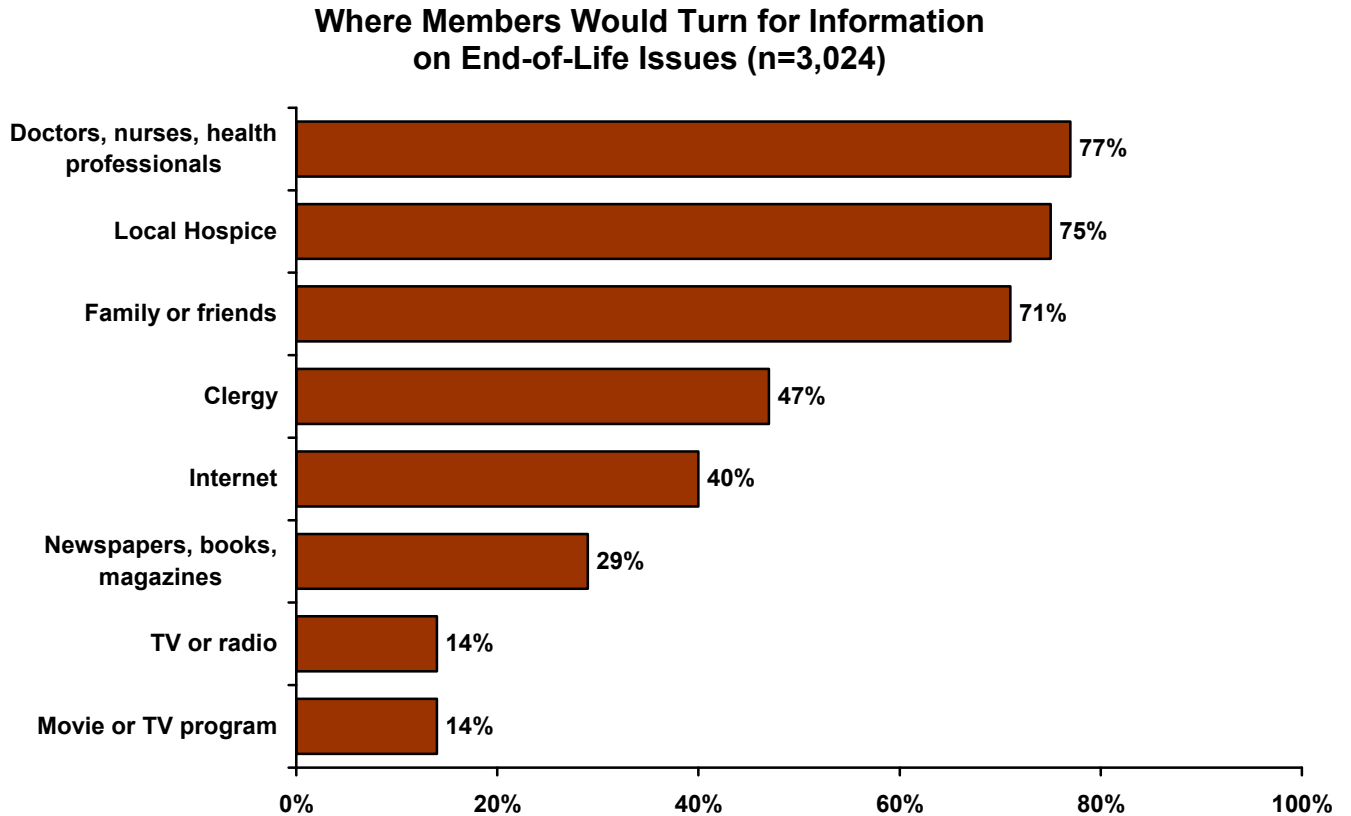
Familiar or not with local Hospice services, over six in ten members (63%) say that they, a family member, or a friend has received services from a Hospice in the past. Of these members, three in four have received these services or know someone who has while in Florida. AARP members have been involved with Hospice to a much lesser extent as volunteers (9%), employees (6%), or by participating in a community program offered by Hospice (11%).

Nearly nine in ten (89%) members agree that a person with a terminal illness, regardless of their diagnosis or life expectancy, should be able to receive Hospice care. Similarly, nearly nine in ten (87%) agree that a person using Medicare to pay for life prolonging treatments like chemotherapy or radiation should be able to receive Hospice care through Medicare if they have a terminal diagnosis. Over seven in ten (73%) also agree that there should be no limit on how much Medicare pays for Hospice services.

End-of-Life Issues

When looking for information on end-of-life issues, over seven in ten members would turn to the following sources: doctors, nurses, or other health professionals; the local Hospice organization, or family and friends.

About half of AARP members would also talk to clergy. Two in five would search the Internet, and about three in ten would turn to the written word in newspapers, books or magazines.

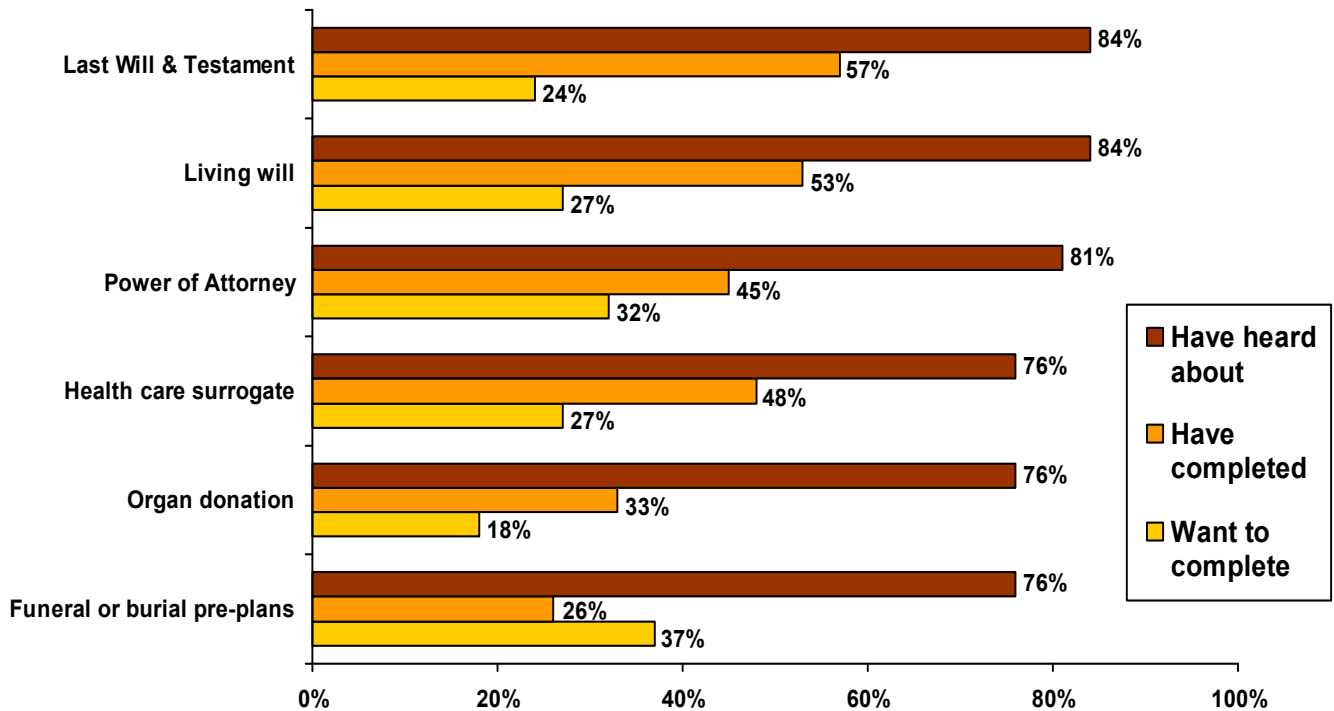


AARP members with higher incomes (\$75,000+) were more likely than members with lower incomes to turn to these information sources – family or friends (78%), health professionals (87%), print media (43%), local Hospice (85%), and the Internet (63%). Members with lower incomes (under \$20,000) were more likely to turn to clergy for information than members with higher incomes (51%).

More AARP members have heard about specific advance directives – making certain health care choices known in advance of an incapacitating illness or death – than have taken steps to complete them.

Over half of members say they have completed a Last Will and Testament and a Living Will. Members who have completed a Last Will and Testament tend to be older (65+, 65%), have household incomes over \$75,000 (69%), and be extremely or very familiar with Hospice (62%). Members who have completed a Living Will are more likely to be older (65+, 62%), a current or former caregiver (59%), or be extremely or very familiar with Hospice (62%).

Members’ Awareness of Advance Directives and Actions Taken to Complete Them (n=3,024)



Nearly half say they have completed a Health Care Surrogate, or a designation in writing naming someone to make medical decisions for them in the event they become incapacitated. These members are also more likely to be older (65+, 56%), a current or former caregiver (55%), and be extremely or very familiar with Hospice (58%). Close to half say they have completed a Durable Power of Attorney, a legal document that designates someone to make decisions about financial and real property interests in the event they become incapacitated. Likewise, these members tend to be older (65+, 55%), be extremely or very familiar with Hospice (52%), or have household incomes over \$75,000 (53%).

One-third of members say they are organ donors, and they are more likely to be younger (50-64, 41%). A quarter says they have already planned or purchased funeral or memorial goods or services for themselves, and these members tend to be older (65+, 34%).

Nearly two in three members (64%) say they have talked to someone about their wishes for care at the end of their life.

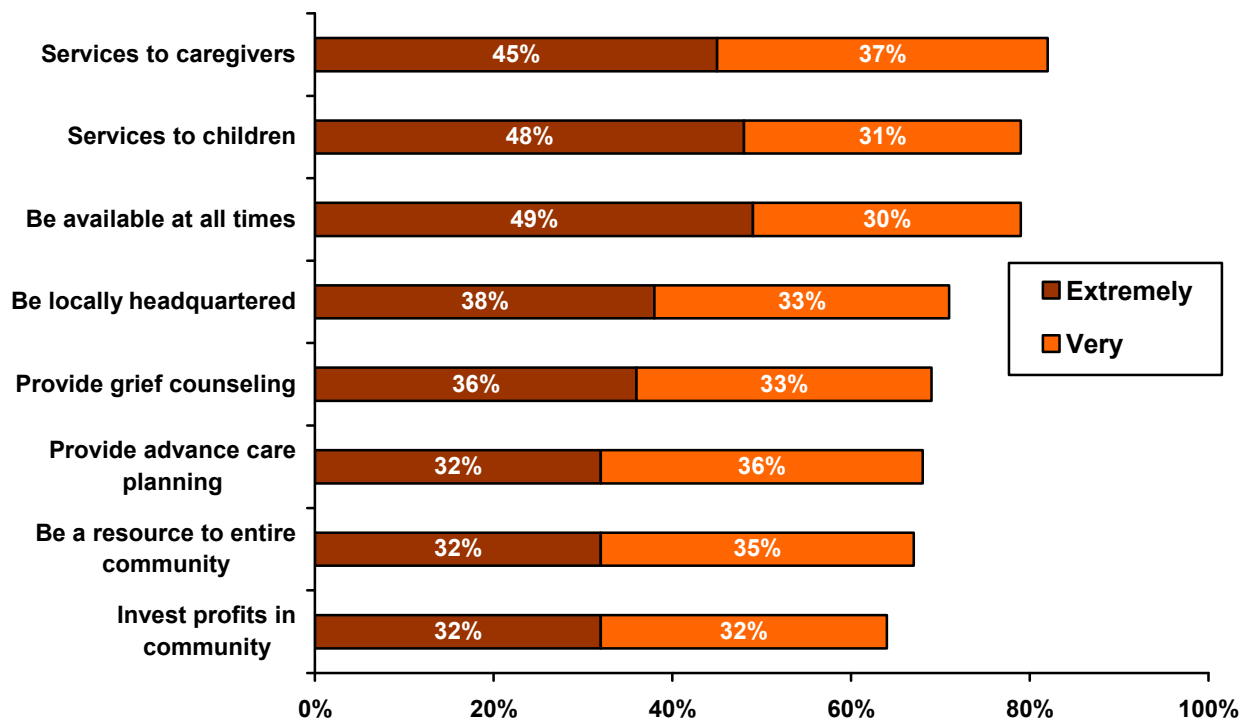
However, one in four members (23%) say they have not talked to someone about their end-of-life wishes. Members who have talked to someone are more likely to be a current or former caregiver (74%), say they are in excellent or very good health (67%), be married (67%), and say they are extremely or very familiar with Hospice (75%). AARP members are most likely to have talked to a family member or spouse about their wishes for care and less likely to have talked to their physician or clergy.

- Family members (75%)
- Spouse or partner (62%)
- Friends (32%)
- Lawyer (27%)
- Physician (14%)
- Clergy (7%)

AARP members say it is extremely or very important for organizations that provide end-of-life care to provide services to caregivers, children, and be available 24/7.

In addition to providing care for its patients, eight in ten AARP members also think it is important that end-of-life care organizations provide services to caregivers and special services to children affected by serious illness, death, and grief. It is also important for such organizations to be available at all times – 24 hours/7 days a week – for patients and their families.

Important Characteristics and Activities for Organizations that Provide End-of-Life Care (n=3,024)



About seven in ten members think it is important for these organizations to be locally headquartered to understand all of the community’s end-of-life needs, offer grief counseling to anyone in the community who needs it, and provide advance care planning services and information to everyone in the community.

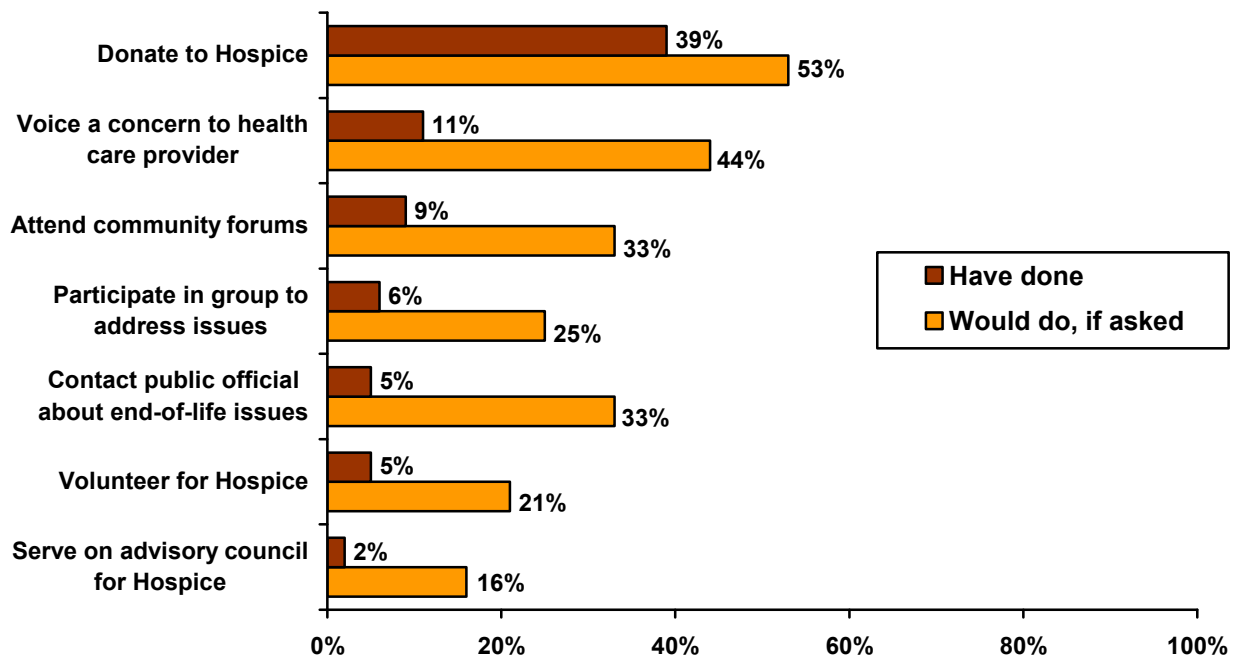
About two in three think these organizations should be an end-of-life resource for the entire community, not just their patients, and invest any profits received from caring for the dying back into the community.

Involvement in End-of-Life Issues

While about four in ten members have donated to Hospice in the past, over half would donate if they were asked. In fact, AARP members are very likely to become involved in end-of-life issues, if someone asks them.

AARP members in Florida clearly would participate more in end-of-life issues, simply if they were asked. In all but one of the seven activities included in the survey, participation would more than double.

Members’ Past and Future Involvement to Improving End-of-Life Care (n=3,024)



If asked, four in ten members say they would voice a concern or complaint to a health care provider about their caregiving, health care, or end-of-life experiences if it would improve services. One in three say they would attend community forums to learn more about end-of-life care issues, and contact a public official to demonstrate support of policies that

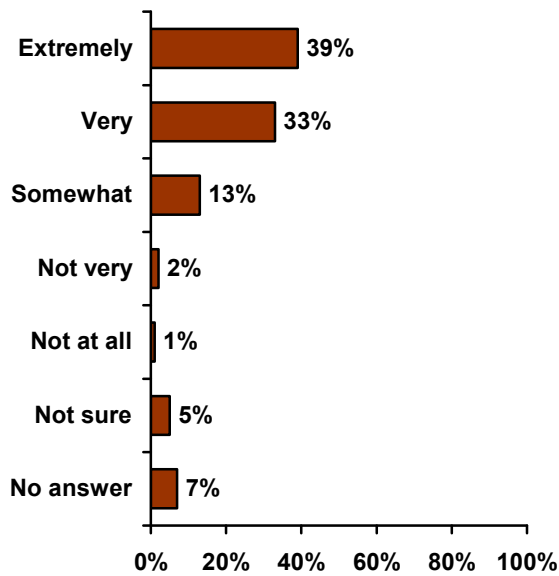
positively impact end-of-life care. One in four would participate in a neighborhood, workplace, or other community group to help address end-of-life or caregiving issues in their community. One in five would volunteer for Hospice, and one in six would serve on an advisory council, focus group, or other community-input group for a Hospice or end-of-life care organization.

Not surprisingly, members with higher incomes and in better health were more likely to engage in community activities to improve end-of-life care and services. They were more likely to volunteer for Hospice, donate to Hospice, contact public officials, serve on advisory boards, attend community forums, voice concerns or complaints, and participate in groups to address end-of-life or caregiving issues in the community.

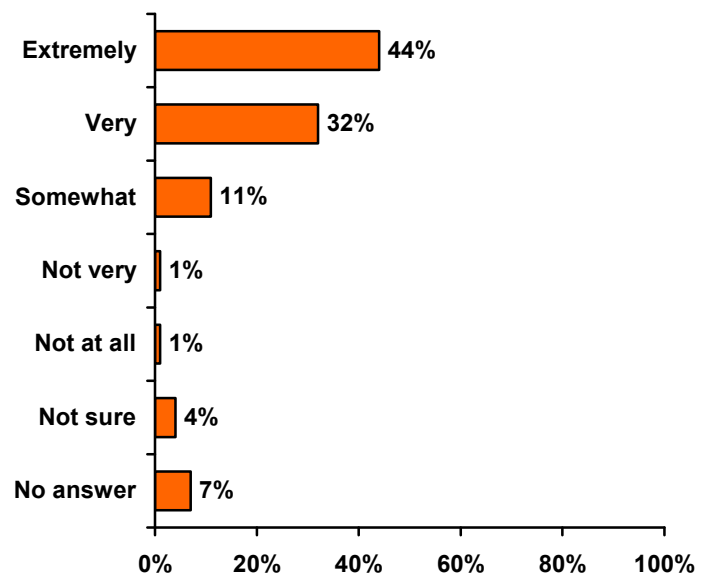
Members are likely to vote for state or local leaders that support strengthening end-of-life care and support community Hospice programs.

Seven in ten members say they are extremely or very likely to vote for state or local leaders that support strengthening end-of-life care. Another 13 percent say they are somewhat likely.

Likelihood of Voting for Leaders that Support Strengthening End-of-Life Care
(n=3,024)



Likelihood of Voting for Leaders that Demonstrate Support of Community Hospice Programs
(n=3,024)



Three in four members say they are extremely or very likely to vote for state or local leaders that demonstrate support of community Hospice programs. Another 11 percent say they are somewhat likely.

Conclusion

Thirteen percent of AARP members in Florida are currently providing unpaid care for a relative or friend 18 and older who is ill, frail, or has some form of disability. The majority of these members has been providing care for more than one year and spends at least eleven hours each week providing care. A recent report by the Public Policy Institute of AARP estimates the economic value of caregiving in Florida at over \$19 billion.

Many caregivers say they find caregiving to be emotionally stressful, and one in five says that more help is needed in providing emotional or social support to the person they care for and more help is needed in the overall management of care. Caregivers would also find helpful information about community caregiving resources and help in providing transportation and finding accurate medical information.

If AARP members had a choice, most would choose to die at home. When members think about death and dying, the majority is concerned about being burdensome to others or that their money will run out. Members also want honest answers from their doctors and want to fully understand their medical options. If members went looking for information about end-of-life issues, most would turn to their doctor, their family and friends, or their local Hospice organization.

Most members are familiar with Hospice services and have a favorable opinion about them. This may explain why if AARP members were asked, half say they would donate to Hospice and one in five say they would volunteer for Hospice. Members also think it is important for such organizations not just to provide services to those who are terminally ill, but also to caregivers and children as well as be available at all times.

Two in three members have talked to someone about their wishes for care at the end of their life, most likely their spouse or another family member. However, fewer have taken concrete steps and completed advance directives like a Last Will and Testament or a Living Will. Even fewer have purchased or planned their funeral or memorial services.

In summary, this survey shows that AARP members are willing to think about, talk about, and become involved in end-of-life issues.

Demographic Profile of Florida Members

Overall Health Rating

Excellent	16%
Very good	35%
Good	28%
Fair	12%
Poor	3%

Have Health Care Coverage

Yes	88%
No	6%
Not sure	<.5%
No answer	6%

Type of Health Care Coverage

Current employer or spouse's current employer	26%
Past employer or spouse's past employer	29%
Own own, through individual insurance policy	27%
Medicare	60%
Medicaid	8%
Veteran's Administration or military benefits	14%

Gender

Male	41%
Female	54%

Age

50-59 years	22%
60-74 years	41%
75+ years	26%

Marital Status

Married	51%
Not married, living with partner	3%
Separated	1%
Divorced	14%
Widowed	19%
Never married	4%

Employment

Employed, full-time	23%
Employed, part-time	10%
Retired	54%

Education

K-12 th grade, no diploma	5%
High school graduate/GED	22%
Post-high school, no degree	17%
2-year college degree	11%
4-year college degree	13%
Post-graduate study, no degree	4%
Graduate or professional degree	15%

Full-Time Florida Resident

Yes	88%
No	5%

Hispanic Origin

	4%
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Race

White or Caucasian	86%
Black or African-American	5%
American Ind. or Alaskan Native	<.5%
Asian	1%
Native Hawaiian or Pac. Islander	<.5%
Other	1%

Income

Less than \$10,000	4%
\$10,000 to \$19,999	11%
\$20,000 to \$29,999	12%
\$30,000 to \$49,999	18%
\$50,000 to \$74,999	17%
\$75,000 to \$99,999	8%
\$100,000 to \$149,999	5%
\$150,000 or more	5%

Methodology

In May 2008, AARP conducted a mail survey of AARP members age 50 and older in Florida. Each respondent was contacted four times receiving the following pieces of mail: a pre-notification postcard, a survey, a reminder postcard, and a second survey. From a random sample of 8,000 members selected from AARP's membership database, a total of 3,024 completed surveys were returned by the cutoff date of June 27th, yielding a response rate of 38 percent.

The survey has a sampling error of ± 1.8 percent. This means that in 95 out of 100 samples like this one, our results fall in a range of ± 1.8 percent of what would have been obtained if every Florida member age 50 and older had been surveyed. Minor weights were applied to the survey results to reflect the distribution of age in the AARP membership of Florida. Weighted responses to all survey questions are found in Appendix A.

APPENDIX A

ANNOTATED QUESTIONNAIRE

AARP Florida Caregiving & End of Life Annotated Survey n=3,024

Your Caregiving Experience

For the purposes of this survey, a caregiver can be anyone who provides unpaid care for a relative, friend, spouse, companion, or partner 18 years or older who is ill, frail, elderly, or has a physical, mental, or emotional disability. Unpaid care may include assisting with personal needs, household chores, meals, shopping, transportation, financial or medical management, arranging for outside services, or a variety of other tasks. The person you provide care for may be someone who lives with you, or somewhere else.

1. Are you currently providing unpaid care for a relative, friend, spouse, companion or partner 18 years or older who is ill, frail, elderly, or has a physical, mental, or emotional disability? n=3,024

13% Yes

79% No → **SKIP TO QUESTION 12**

7% Missing/No answer

2. How many people are you currently providing care for? n=403

50% 1

12% 2

1% 3

1% 4

<0.5% 5

1% 6 or more

37% Missing/No answer

For questions 3-8, if you provide care for more than one person, please describe the person with whom you spend most of your caregiving time.

3. Does the person you provide care for live with you? n=403

52% Yes → **SKIP TO QUESTION 6**

39% No

9% Missing/No answer

4. How far away from you does the person you provide care for live? n=158

47% Less than 15 minutes away

26% 15 minutes to 30 minutes away

8% 31 to 59 minutes away

9% 1 to 4 hours away

7% More than 4 hours away

4% Missing/No answer

5. Where does the person you provide care for live? n=158

- 22% In an assisted living residence
- 6% In a nursing home
- 63% In his or her home
- 5% In a friend or relative's home
- 0% In a hospice residence
- 1% Other (Please specify)
- 3% Missing/No answer

6. Below is a list of caregiving tasks. For tasks a-h, please answer all 3 parts of this question by indicating whether... n=403

**You perform this caregiving task;
 Others perform this caregiving task;
 The person you care for needs more help in this area than is currently provided.**

	You perform			Others perform			More help is needed		
	Yes	No	NA	Yes	No	NA	Yes	No	NA
Personal Care (bathing, dressing, feeding, toileting)	28%	53%	20%	25%	35%	40%	13%	42%	45%
Household (grocery shopping, house cleaning, yard work, maintenance)	73%	14%	13%	28%	26%	47%	17%	34%	49%
Financial (budgeting, paying bills, managing bills)	70%	16%	14%	13%	36%	51%	13%	36%	52%
Emotional/Social Support (listening, loving, companionship, activities, support)	85%	3%	12%	36%	17%	47%	20%	29%	51%
Spiritual Support (attending religious services, praying together, serving others)	47%	38%	15%	23%	33%	44%	14%	38%	48%
Transportation (driving to appointments, running errands)	80%	9%	11%	27%	26%	47%	15%	34%	51%
Medical (scheduling doctor appointments, helping understand treatment options, giving medicines)	72%	15%	12%	22%	33%	45%	13%	38%	49%
Overall Management of Care (making decisions about living arrangements, insurance benefits, determining how to get services, finding and connecting with community resources)	72%	15%	13%	22%	32%	46%	20%	32%	48%

7. How long have you been providing care for this person? n=403

- 13% Less than one year
- 45% 1 to 5 years
- 19% 6 to 10 years
- 7% 11 to 15 years
- 7% More than 15 years
- 10% Missing/No answer

8. Considering all the types of care you provide for this person, how much time do you spend in an average week doing these things? n=403

- 12% Less than 5 hours a week
- 22% 6 to 10 hours a week
- 17% 11 to 20 hours a week
- 11% 21 to 30 hours a week
- 8% 31 to 40 hours a week
- 6% 41 to 60 hours a week
- 4% 61 to 80 hours a week
- 11% More than 80 hours a week
- 9% Missing/No answer

For questions 9-11, if you provide care for more than one person, please describe your overall caregiving experience.

9. How stressful is it for you to provide care? n=403

	Extremely	Very	Somewhat	Not very	Not at all	Missing/No answer
a. Physically stressful	6%	10%	29%	14%	11%	30%
b. Emotionally stressful	16%	23%	21%	8%	3%	29%
c. Financially stressful	9%	10%	24%	15%	14%	29%

10. How helpful would the following types of support be to you as a caregiver? n=403

	Extremely helpful	Very helpful	Some-what helpful	Not very helpful	Not at all helpful	Missing/No answer
a. Assistance with providing transportation	16%	16%	14%	13%	14%	28%
b. Assistance with finding accurate medical information.....	15%	16%	18%	8%	14%	28%
c. Connecting with other caregivers in similar situations.....	8%	10%	22%	16%	15%	29%

	Extremely helpful	Very helpful	Some-what helpful	Not very helpful	Not at all helpful	Missing/No answer
d. Guidance and help in understanding medical bills.....	10%	12%	17%	15%	17%	29%
e. Spiritual support and/or guidance.....	9%	11%	18%	13%	18%	30%
f. Information about available resources for caregivers in my community.....	21%	20%	14%	6%	11%	28%
g. Short breaks (hours) from my caregiving tasks	11%	15%	13%	14%	19%	28%
h. Longer breaks (days) from my caregiving tasks	13%	13%	14%	12%	20%	29%

**11. Is there any other kind of support that would be helpful to you as a caregiver?
n=403**

- 3% Financial / winning the lottery
- 2% Time off / relief from care giving tasks
- 2% More family involvement / assistance from siblings
- 2% Not at this time
- 2% Housekeeper / domestic help
- 2% Companionship / friends coming to visit
- 12% All other mentions
- 7% None / nothing
- 72% Missing/No answer

End-of-Life Care and Services

12. Have you ever heard of hospice services? n=3,024

- 90% Yes
- 5% No → *SKIP TO QUESTION 18*
- 6% Missing/No answer

**13. How familiar are you with the hospice or hospice services in your community?
n=2,714**

- 12% Extremely familiar
- 18% Very familiar
- 37% Somewhat familiar
- 18% Not very familiar
- 13% Not at all familiar
- 1% Not sure
- 2% Missing/No answer

14. Have you, a family member, or a friend ever...? n=2,714

	Yes, in Florida	Yes, outside Florida	No	Missing/ No answer
a. Received services from a hospice	47%	16%	27%	10%
b. Volunteered for a hospice	7%	2%	67%	24%
c. Been employed by a hospice.....	5%	1%	69%	26%
d. Participated in any of the community programs offered by a hospice	9%	2%	65%	24%

15. What is your overall opinion of hospice? n=2,714

- 46% Extremely favorable
- 34% Very favorable
- 9% Somewhat favorable
- 1% Not very favorable
- <0.5% Not at all favorable
- 7% Not sure
- 3% Missing/No answer

16. To the best of your knowledge, does Medicare pay for hospice services? n=2,714

- 31% Yes
- 7% No
- 60% Not sure
- 3% Missing/No answer

17. How strongly do you agree or disagree with the following statements? n=2,714

	Strongly agree	Some- what agree	Neither agree nor disagree	Some- what disagree	Strongly disagree	Missing/ No answer
a. A person with a terminal illness, regardless of diagnosis or life expectancy, should be able to receive hospice care	74%	15%	6%	2%	1%	3%
b. A person using Medicare benefits to pay for life-prolonging treatments like chemotherapy or radiation should also be allowed to receive hospice services through Medicare if they have a terminal diagnosis.....	73%	14%	5%	3%	1% 3%	

	Strongly agree	Some-what agree	Neither agree nor disagree	Some-what disagree	Strongly disagree	Missing/ No answer
c. There should be no limit to how much Medicare pays for hospice services for any person.....	51%	22%	12%	7%	4%	5%

18. When you think about death and dying, how concerned are you that...? n=3,024

	Extremely concerned	Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	Missing/ No Answer
a. My money or my family's money won't last	30%	23%	25%	10%	5%	6%
b. I will be a burden to others	32%	25%	24%	9%	5%	6%
c. I will be afraid to die	7%	8%	22%	26%	29%	9%
d. I will suffer while dying	21%	21%	29%	13%	9%	8%
e. I will die in pain.....	21%	21%	28%	14%	8%	8%
f. I will die alone	12%	12%	22%	24%	24%	8%

19. If you were looking for information on end-of-life issues (e.g., dying well, care options, grief, or caregiving for someone who is dying), would you be likely to turn to the following resources? n=3,024

	Yes	No	Not sure	Missing/ No Answer
a. Family or friends	71%	8%	11%	10%
b. Doctors, nurses or other health professionals.....	77%	5%	9%	10%
c. Clergy (minister, rabbi, priest, etc.).....	47%	22%	18%	13%
d. Newspapers, books or magazines	29%	35%	20%	16%
e. Television or radio	14%	51%	18%	17%
f. Local hospice organization	75%	5%	10%	10%
g. Internet or World Wide Web	40%	28%	17%	15%
h. A movie or TV program on death and dying	14%	49%	21%	16%

20. If you were terminally ill and could choose where to die, where would you MOST want to die? (Choose only ONE answer.) n=3,024

- 58% At home
- 1% In an assisted living residence
- 15% In a hospice residence
- 1% In a nursing home
- 4% In a hospital
- 12% I have no preference
- 1% Other (Please specify)
- 8% Missing/No answer

21. How important would each of the following be to you in dealing with your own dying? n=3,024

	Extremely important	Very important	Somewhat important	Not very important	Not at all important	Missing/No answer
a. Personal care aides or companions you could hire to help care for you	32%	30%	22%	5%	3%	9%
b. Getting all the services you need from one provider as your condition changes (i.e., “seamless” care).....	39%	34%	15%	3%	1%	8%
c. Getting help early - services long before you are dying to meet your needs as your condition changes.....	37%	34%	18%	3%	1%	7%
d. Expert pain control services and consultations	51%	30%	9%	2%	1%	8%
e. Honest answers from your doctor	74%	17%	2%	<0.5%	<0.5%	7%
f. Comfort from religious/spiritual services or persons	37%	20%	20%	8%	7%	8%
g. Knowing medicines are available to you	58%	28%	5%	1%	1%	7%
h. Planning your own funeral.....	32%	22%	23%	10%	6%	7%
i. Being able to complete your Last Will and Testament, distributing your personal assets.	55%	25%	9%	2%	2%	7%
j. Fulfilling personal goals or pleasures.....	27%	25%	26%	10%	4%	8%

	Extremely important	Very important	Somewhat important	Not very important	Not at all important	Missing/ No answer
k. Being off machines that extend life (life support)	54%	24%	10%	3%	2%	7%
l. Having health care professionals (doctors, nurses, etc.) visit you at your home	38%	31%	18%	4%	2%	7%
m. Getting your finances in order	52%	30%	8%	2%	2%	7%
n. Understanding your medical treatment options.....	64%	26%	3%	<0.5%	1%	6%
o. Giving others your time, gifts, or wisdom.....	33%	31%	21%	6%	3%	7%

22. How important is it for an organization that provides end-of-life care to have the following characteristics or engage in the following activities? n=3,024

	Extremely important	Very important	Somewhat important	Not very important	Not at all important	Missing/ No answer
a. Provide specific services for caregivers	45%	37%	8%	1%	1%	8%
b. Serve as an end-of-life resource for the entire community, not just for their patients	32%	35%	20%	4%	2%	9%
c. Provide special services for children affected by serious illness, death, and grief	48%	31%	10%	2%	2%	8%
d. Offer grief counseling to anyone in the community who needs it	36%	33%	19%	3%	2%	7%
e. Be locally headquartered to understand all of the community's end-of-life needs	38%	33%	16%	3%	1%	8%
f. Be available at all times (24 hours/7 days a week) for patients and families.....	49%	30%	10%	2%	1%	8%
g. Invest any profits from caring for the dying back into the community	32%	32%	20%	5%	3%	8%
h. Provide advance care planning services and information to everyone in the community.....	32%	36%	19%	4%	2%	8%

Advance Care Planning and Preparation

23. Advance directives allow people to make their health care choices known in advance of an incapacitating illness or death. Which of the following advance directives or pre-plans have you heard about? Which have you completed? For a-f, please answer whether you have heard about it and whether you have completed it. n=3,024

	Have heard about			Have completed	Want to complete but have not	Do not want to complete	Missing/ No answer
	Yes	No	Missing/ No answer				
a. <u>Designation of Health Care Surrogate</u> , naming in writing someone to make medical decisions for you in the event you become incapacitated.....	76%	11%	13%	48%	27%	4%	21%
b. <u>Durable Power of Attorney</u> , a legal document that names someone who will make decisions about your financial and real property interests in the event you become incapacitated.....	81%	6%	13%	45% 32%		4%	19%
c. <u>Living Will</u> , indicating in writing the kinds of health care and medical treatments you want or don't want under certain circumstances, so your choices are known if you can't communicate for yourself	84%	3%	14%	53%	27%	2%	18%
d. <u>Will or Last Will and Testament</u> , a legal document that designates how your assets are to be distributed after you die	84%	2%	14%	57% 24%		2%	18%
e. <u>Funeral or Burial Pre-Plans</u> , planning or purchasing funeral or memorial services or goods for yourself in advance.....	76%	10%	13%	26%	37%	18%	19%
f. <u>Organ Donation</u> , indicating that your organs and/or tissue will be donated after you die for use by others in need of transplants	76%	11%	13%	33% 18%		29%	20%

24. Whether or not you have completed any advance directives or pre-plans, have you talked with anyone about your wishes for care at the end of your life? n=3,024

64% Yes
 23% No → *SKIP TO QUESTION 26*
 13% Missing/No answer

25. With whom have you talked about your wishes for care at the end of your life? n=1,931

	Yes	No	Missing/ No answer
a. Spouse or partner	62%	14%	24%
b. Family members (other than spouse or partner)	75%	12%	12%
c. Clergy (minister, rabbi, priest, etc.)	7%	57%	36%
d. Friends	32%	37%	31%
e. Lawyer	27%	41%	32%
f. Primary physician	14%	49%	37%
g. Other, please specify: _____	1%	99%	NA

Your Involvement

26. There are a variety of ways that community members can become involved in improving end-of-life care. Have you ever ...? n=3,024

	Yes	No	Missing/ No answer
a. Volunteered for hospice	5%	89%	6%
b. Donated to the local hospice.....	39%	54%	7%
c. Contacted a public official to demonstrate support of policies that positively impact end-of-life care	5%	88%	7%
d. Served on an advisory council, focus group, or other “community input” group for a hospice or end-of-life organization.....	2%	91%	7%
e. Attended community forums to learn about end-of-life care issues.....	9%	83%	8%
f. Voiced a concern or complaint to a health care provider about your caregiving, health care, or end-of-life experience	11%	82%	7%
g. Participated in a neighborhood, workplace, or other community group to help address end-of-life or caregiving issues in your community	6%	88%	7%

27. If you were asked to, would you be likely in the future to engage in the following activities to improve end-of-life care and services? n=3,024

	Yes	No	Not sure	Missing/No answer
a. Volunteer for the local hospice.....	21%	34%	38%	7%
b. Donate to the local hospice.....	53%	13%	27%	7%
c. Contact a public official to demonstrate support of policies that positively impact end-of-life care.....	33%	26%	33%	8%
d. Serve on an advisory council, focus group, or other “community input” group for a hospice or end-of-life care organization	16%	44%	33%	8%
e. Attend community forums to learn about end-of-life care issues.....	33%	30%	29%	7%
f. Voice a concern or complaint to a health care provider about your caregiving, health care, or end-of-life experience.....	44%	23%	26%	7%
g. Participate in a neighborhood, workplace, or other community group to help address end-of-life or caregiving issues in your community	25%	31%	37%	7%

28. How likely are you to vote for state or local leaders that support strengthening end-of-life care? n=3,024

- 39% Extremely likely
- 33% Very likely
- 13% Somewhat likely
- 2% Not very likely
- 1% Not at all likely
- 5% Not sure
- 7% Missing/No answer

29. How likely are you to vote for state or local leaders that demonstrate support of community hospice programs? n=3,024

- 44% Extremely likely
- 32% Very likely
- 11% Somewhat likely
- 1% Not very likely
- 1% Not at all likely
- 4% Not sure
- 7% Missing/No answer

30. In what other ways are you likely to get involved in improving end-of-life care issues? n=3,024

- 2% Already involved due to job / family illness
- 1% I'm in poor health / disabled
- 1% Discuss / communicate with family / friends / neighbors on planning
- 1% In any way I can / as I'm needed
- 1% Become more informed / be ready / prepared / get my affairs in order
- 1% Give care to end of life people / personally helping family / friends
- 1% Help raise money / donate money to hospice
- 1% Too old to get involved
- 1% Volunteer / at nursing homes / community groups / donate time
- 1% Unable to get involved / participate
- 1% I do not do volunteer work / leave my home / don't like to get involved
- 1% Work with hospice / volunteer at hospice
- 1% Would consider in the future / somewhat likely to participate
- 1% Promote legislation / write letters / support political initiatives
- 6% All other mentions
- 2% None
- 4% Don't know
- 81% Missing/No answer

About You

The following questions are for classification purposes only and will be kept entirely confidential.

D1. In general, how would you rate your own health right now? n=3,024

- 16% Excellent
- 35% Very good
- 28% Good
- 12% Fair
- 3% Poor
- 6% Missing/No answer

D2. Do you have any kind of health care coverage, including employer-provided health insurance, private health insurance, or government plans such as Medicare or Medicaid? n=3,024

- 88% Yes
- 6% No → **SKIP TO QUESTION D4**
- <0.5% Not sure → **SKIP TO QUESTION D4**
- 6% Missing/No answer

D3. Do you have health care coverage through the following sources? n=2,658

	Yes	No	Missing/ No answer
a. Current employer or spouse's current employer.....	26%	50%	24%
b. Past employer or spouse's past employer (may be a retirement benefit).....	29%	47%	24%
c. On your own through an individual insurance policy.....	27%	45%	28%
d. Medicare	60%	24%	17%
e. Medicaid.....	8%	55%	37%
f. Veteran's Administration (VA) or military benefits.....	14%	52%	34%
g. Other (Please specify) _____	9%	91%	NA

D4. In the last 12 months, how many times have you received services for yourself at an emergency room? n=3,024

- 63% None
- 13% 1
- 5% 2
- 1% 3
- 1% 4
- <0.5% 5
- 0% 6
- 0% 7
- 0% 8
- 0% 9
- <0.5% 10 or more
- 17% Missing/No answer

D5. In the last 12 months, how many days have you stayed overnight in a hospital? n=3,024

- 67% None
- 3% 1
- 3% 2
- 2% 3
- 2% 4
- 2% 5
- 1% 6
- 1% 7
- <0.5% 8
- <0.5% 9
- 3% 10 or more
- 17% Missing/No answer

D6. Thinking about your state elections for Florida Governor and Legislators in the last ten years, how often would you say you vote? n=3,024

- 63% Always
- 19% Most of the time
- 4% About half of the time
- 4% Seldom
- 5% Never
- 6% Missing/No answer

D7. Are you male or female? n=3,024

- 41% Male
- 54% Female
- 6% Missing/No answer

D8. What is your age as of your last birthday? _____ (AGE IN YEARS) n=3,024

- 22% 50 – 59
- 41% 60 – 74
- 26% 75 or older
- 12% Missing / No Answer

D9. Does any disability, handicap, or chronic disease keep you from participating fully in work, school, housework, or other activities? n=3,024

- 25% Yes
- 66% No
- 9% Missing/No answer

D10. What is your current marital status? n=3,024

- 51% Married
- 3% Not married, living with partner
- 1% Separated
- 14% Divorced
- 19% Widowed
- 4% Never married
- 9% Missing/No answer

D11. Where do you live? n=3,024

- 85% In my home
- 1% In an assisted living residence
- <0.5% In a nursing home
- 3% In a friend or relative's home
- <0.5% In a hospice residence
- 2% All other mentions
- 10% Missing/No answer

D12. Which of the following best describes your current employment status? n=3,024

- 4% Self-employed, part-time
- 4% Self-employed, full-time
- 7% Employed, part-time
- 19% Employed, full-time
- 54% Retired, not working at all
- 3% Not in labor force for other reasons
- 2% Unemployed but looking for work
- 8% Missing/No answer

D13. What is the highest level of education you have completed? n=3,024

- 5% K-12th grade (no diploma)
- 22% High school graduate, GED or equivalent
- 17% Post-high school education/training (no degree)
- 11% 2-year college degree
- 13% 4-year college degree
- 4% Post-graduate study (no degree)
- 15% Graduate or professional degree(s)
- 12% Missing/No answer

D14. What is your 5-digit Florida ZIP Code? _____

D15. Are you a full-time (year-round) Florida resident? n=3,024

- 88% Yes
- 5% No
- 7% Missing / No Answer

D16. Are you of Spanish, Hispanic or Latino origin or descent? n=3,024

- 4% Yes
- 89% No
- 7% Missing/No answer

D17. What is your race? n=3,024

- 86% White or Caucasian
- 5% Black or African-American
- <0.5% American Indian or Alaska Native
- 1% Asian
- <0.5% Native Hawaiian or other Pacific Islander
- 1% Other
- 8% Missing/No answer

D18. What was your annual household income before taxes in 2007? n=3,024

- 4% Less than \$10,000
- 11% \$10,000 to \$19,999
- 12% \$20,000 to \$29,999
- 18% \$30,000 to \$49,999
- 17% \$50,000 to \$74,999
- 8% \$75,000 to \$99,000
- 7% \$100,000 to \$149,000
- 5% \$150,000 or more
- 5% Not sure
- 13% Missing/No answer

Thank you very much for completing this survey.
Please return your completed survey by July 28, 2008
in the enclosed postage-paid envelope to:
AARP State Research
601 E Street, NW
Washington, DC 20049



AARP

Knowledge Management

For more information, please contact Terri Guengerich at:

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