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AARP Massachusetts End of Life Survey

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August 2005



AARP Massachusetts End of Life Survey

**Report Prepared by
Erica Dinger, J.D.**

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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. We produce *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our bimonthly magazine in Spanish and English; *NRTA Live & Learn*, our quarterly newsletter for 50+ educators; and our website, www.aarp.org. AARP Foundation is our 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.

The Massachusetts Commission on End of Life Care is a state legislative commission that was established in 2001 to identify ways to “improve the quality of life at the end of life.” The Commission fosters public, professional and institutional awareness about end of life issues and promotes professional and consumer education to improve care at the end of life.

The Commission has developed a *Massachusetts Resource Guide for End-of-Life Services*, a guide to information and resources in Massachusetts to assist families and people of all ages facing life-threatening conditions. Copies have been distributed to libraries, hospitals, Councils on Aging, Boards of Health and hospices throughout Massachusetts. The Commission has also created an online searchable database of available resources. For more information about the Commission and its work, visit its website at www.endoflifecommission.org.

Acknowledgements

This study is the result of a partnership between AARP Massachusetts and the Massachusetts Commission on End of life Care. Special thanks for their leadership and vision go to Deborah Banda, State Director, AARP Massachusetts and Margaret Ann Metzger, Executive Director of the Massachusetts Commission on End of Life Care. We also express our gratitude to Ruth Palombo, Chair of the Massachusetts Commission on End of Life Care and Barbara Spring, Ph.D., Director of Research and Programs at the Life’s End Institute: Missoula Demonstration Project.

AARP staff from the Massachusetts State Office and Knowledge Management contributed to the design and implementation of this study. We thank Gretchen Straw, Katherine Bridges, Rachelle Cummins, Darlene Matthews, Cheryl Barnes, and Jennifer Leslie, AARP Knowledge Management. Don McLennan of FGI, Inc. managed data entry and tabulation of the final survey results. Erica Dinger, AARP Knowledge Management, managed this study. For more information, contact Erica Dinger at (202) 434-6176 or edinger@aarp.org.

Executive Summary

Massachusetts is facing an aging population: today, 13.5 percent of Massachusetts residents are 65 or older, but this number will grow to 21 percent, or almost a million and a half people, by 2030.¹ These demographics provide a variety of challenges and opportunities, including providing the information and tools aging residents need to make informed decisions about their end of life needs. This survey was designed to provide information about current thoughts and attitudes on end of life issues. The survey was sent to 3,000 AARP members age 50 and older in Massachusetts in March, 2005. A total of 1,448 AARP members responded, which yielded a 48 percent response rate.

Massachusetts AARP members say they are at least somewhat comfortable talking about death (84%). Most say they would likely attend a funeral or memorial service and to telephone or visit friends who have lost a loved one. Although they may be comfortable talking about death, most say they have only spoken to family about their end of life wishes. Over half say they have spoken to their spouse, partner, or family about their wishes, while only 17 percent have spoken to a physician. Fully ten percent have not spoken to anyone about their end of life wishes.

Members are concerned about their quality of life at the end of life. Nine in ten feel that total physical dependency would be worse than death, and seven in ten say that living in great pain or not being able to communicate their wishes would be worse than death. Pain is also of great concern, with over eight in ten saying they fear dying painfully.

Three-quarters of members say that being free from pain is very important to them, and 83 percent say having good pain management is very important. Over four in ten, however, fear that their doctor may not believe they are in pain. Communicating with their doctor is a concern, with over eight in ten saying honest answers from their doctor is very important to them.

Despite this fear of pain, Massachusetts members report not wanting to take too much pain medication. Almost three-quarters say they would take pain medicine only when the pain becomes severe, and 71 percent say they would take the lowest amount of medicine possible and save larger doses for when the pain is worse. Fully one-third fear becoming addicted to pain medication.

Massachusetts AARP members expect their spouses, partners, and family members to provide support to them at the end of life. They want people to listen to them, know about their illness, and know about their decisions for end of life. Although they want their family to know their decisions, not all members have made advanced planning arrangements. While 69 percent have completed a last will and testament, fewer have completed other advanced planning documents such as a health care proxy, a living will, or other written instructions.

¹ U.S. Census Bureau, Population Division, Interim State Population Projections, Table 5 (2005).

Finally, many members know about Hospice services, with 56 percent saying they have heard a lot about Hospice. Most often, members are informed about Hospice from someone they know who has used it. Of those who know about Hospice, three-quarters say they would use it if they were dying. However, only 40 percent are aware that Medicare will pay for such care.

Massachusetts members are comfortable talking about death and dying, but most restrict such conversations to family members or spouses. While they indicate that having their end of life wishes known is important, not all have taken steps to ensure that their end of life concerns and desires are addressed. Although many fear dying painfully, they also fear addiction to pain medication or over-medication. In sum, Massachusetts members are willing to think and talk about these important end of life decisions, but they need help to start these conversations and understand end of life care issues. This provides an opportunity for the medical, legal, and spiritual professionals in Massachusetts. Professionals well-versed in end of life issues can help their clients have these important conversations and make well-informed decisions for their end of life care.

Highlights

The AARP Massachusetts End of Life Survey provides a comprehensive view of the concerns and attitudes toward end of life issues of AARP members age 50 and older in Massachusetts. The survey was conducted in March and April 2005. A total of 1,448 AARP members responded yielding a 48 percent response rate.

Talking and Thinking About Death

- Eighty-four percent of Massachusetts AARP members report being at least somewhat comfortable talking about death. Most say they are likely to attend funerals or memorials and to telephone or visit friends or relatives who have lost a loved one.
- Over half of members say they have spoken to their spouse, partner, or family about their end of life wishes.
- Only 17 percent report that they have talked with their physicians about their wishes for end of life care, and 10 percent say they have not talked to anyone.

End of Life Concerns

- Members are concerned about various end of life scenarios:
 - Almost 90 percent say that total physical dependency would be worse than death, and about 70 percent say that not being able to communicate their wishes or that living with great pain is worse than death.
 - Over eight in ten Massachusetts AARP members fear dying painfully, and three-quarters fear dying from a long illness.
 - Sixty-two percent are concerned that they will be a financial burden to family and friends.

Pain Management

- Three-quarters of members say that being free from pain is very important to them, and 43 percent say they are afraid their doctor may not believe they are in pain.
- In spite of concerns about pain, AARP members do not want to take too much pain medication:
 - Almost three-quarters agree that they would only take pain medicine when the pain is severe, and 71 percent agree that they would take the lowest amount of medicine possible and save larger doses for later when the pain is worse.
 - One-third fear becoming addicted to pain medicine.

End of Life Needs

- At least eight in ten AARP members in Massachusetts rate the following as very important when dealing with their own dying or thinking about dying:
 - Honest answers from doctors (89%)
 - Understanding treatment options (87%)
 - Not being a physical burden to loved ones (84%)
 - Having good pain management available (83%)
 - Knowing medicine is available (81%)

Advance Care Planning

- Although 69 percent of members say they have completed a last will and testament, fewer have taken other steps for advance care planning:
 - Six in ten have a health care proxy or durable power of attorney
 - Fewer than half have a living will or other written instructions of their wishes

Support from Others

- When asked about support they expect to need near the end of their lives, AARP members in Massachusetts report a variety of needs:
 - Listen to them (84%)
 - Help with chores (84%)
 - Know what they want when they die (82%)
 - Know about the illness (83%)
 - Encourage them when they are down (78%)
 - Provide transportation (76%)
 - Do fun things with them (71%)
 - Help care for other relatives (65%)
- At least seven in ten expect their children to provide each type of support, and almost as many expect their spouse/partner to provide these types of support.

Hospice Services

- More than 90 percent say they have heard of hospice, although fewer than four in ten know that Medicare pays for it.
- Awareness of hospice usually comes from knowing someone who used hospice services (68%).
- Among those who know about hospice, three-quarters would want hospice support if they were dying.

Background

To improve end of life experiences, AARP engages in education, information, advocacy, research, volunteer engagement, and partnerships with key external stakeholders. AARP wants to help people and their families, especially with advance directives, palliative care, and bereavement support. In 2004, AARP Massachusetts and The Massachusetts Commission on End of Life Care joined together to better understand how Massachusetts residents deal with end of life issues. This survey explores AARP members'

- Thoughts about death and dying
- Preparation and planning for death
- Opinions about dealing with the physical, psychological, and financial aspects of dying
- Need for support from people or organizations at the end of life
- Awareness of hospice at the end of life

The survey is based on the Life's End Institute: *Missoula Demonstration Project's* Community Survey. AARP mailed the questionnaire in March/April 2005 to a random sample of 3,000 AARP members in Massachusetts. More than 1,440 responded for a response rate of 48 percent. The survey has a sampling error of plus or minus 1.7 percent. It should be noted that this survey was in the field when the Terry Schiavo case was receiving media attention.

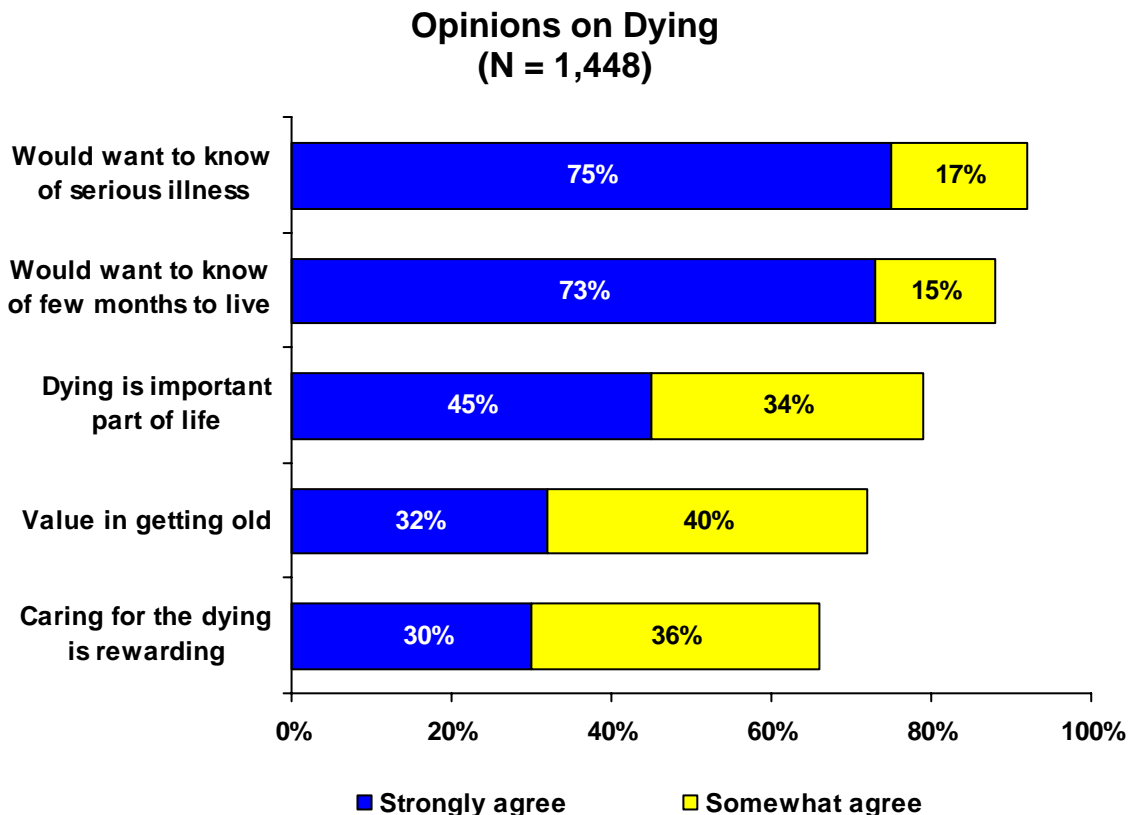
Detailed Findings

Thoughts About Death and Dying

Most respondents report that during their childhood their families rarely (43%) or never (16%) talked about death and dying. Three in ten (30%) say their families had such discussions occasionally, while only five percent had them often.

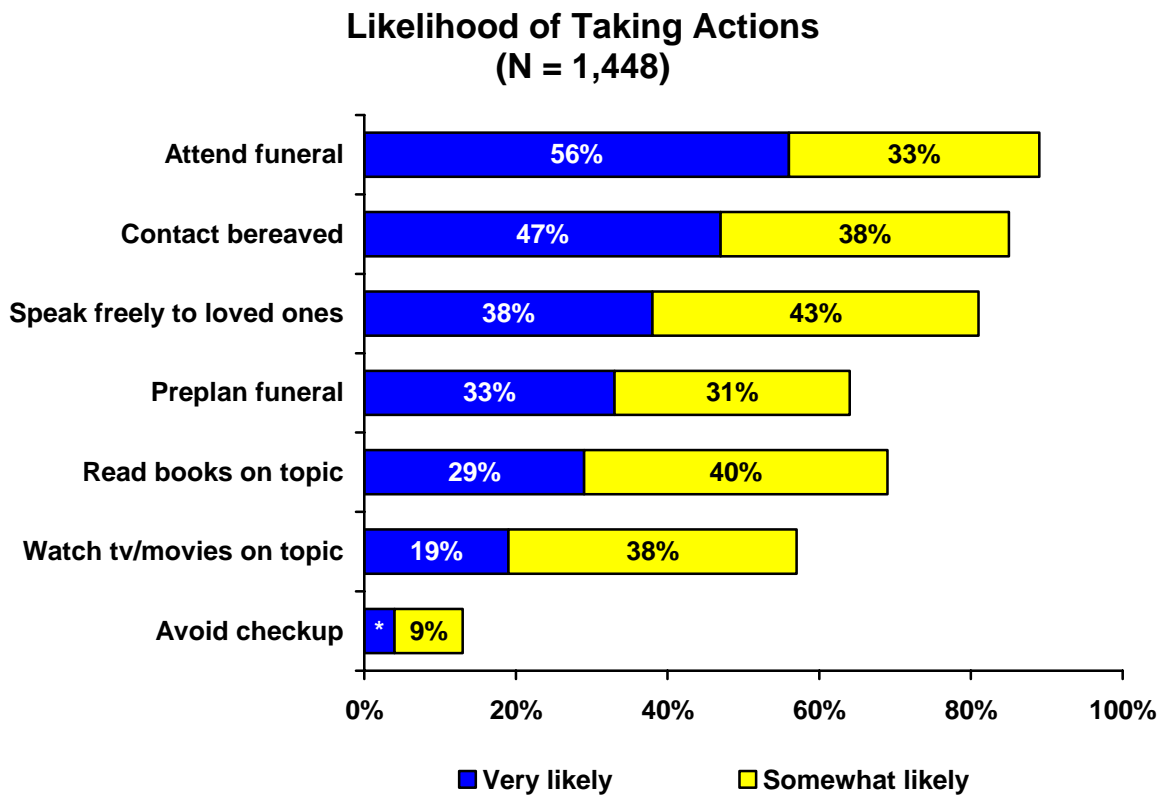
Most (84%) Massachusetts AARP members say they are comfortable talking about death (45% very comfortable and 39% somewhat comfortable). Similarly, 81 percent say they are very (38%) or somewhat (43%) likely to speak freely to loved ones about death and dying.

Over eight in ten say that they would want to know if they had a serious illness or only a few months to live. About seven in ten members agree that dying is an important part of life and that there is special value in getting old. Two-thirds agree that caring for people who are dying is a rewarding experience.



This survey also explored the likelihood that members would engage in a wide range of actions related to death and dying.

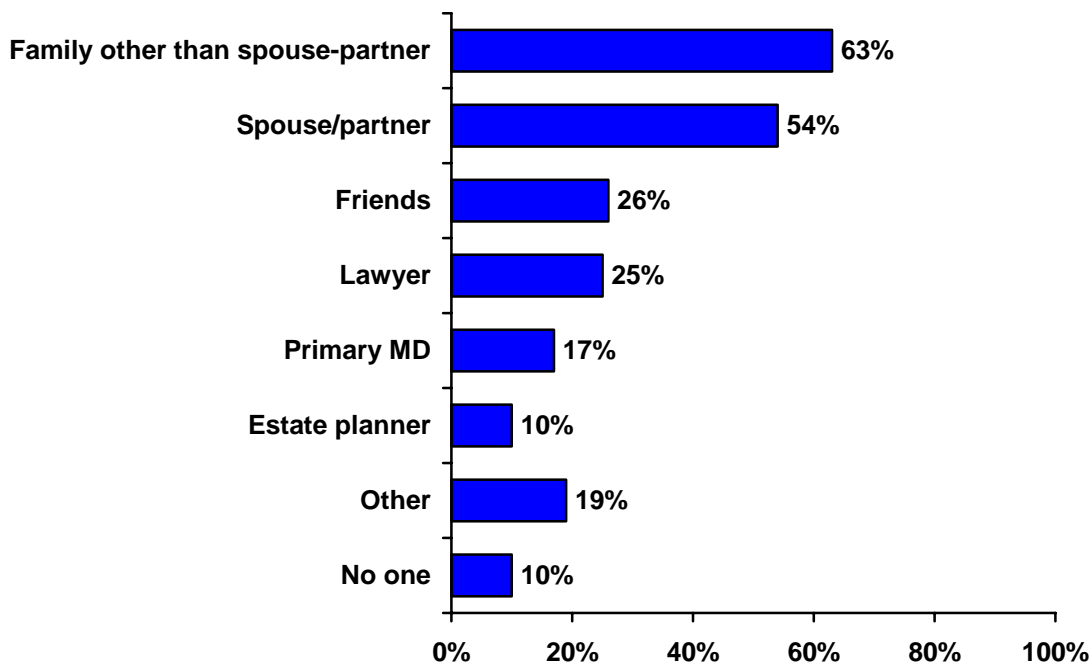
- A majority of members say they are likely to attend funerals or memorial services and to visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing.
- About six in ten members say they are likely to read books, articles, or watch television programs that deal with death and dying.
- Few members are likely to avoid medical checkups because of fear that the doctor will find something serious.



* Less than 5%

Many AARP members in Massachusetts say they have spoken to their family members or to a spouse or partner about their end of life wishes. Fourteen percent have only spoken to family members, while 11 percent have only spoken to their spouse or partner. Two-thirds (65%) say they have spoken to either a family member or to a spouse or partner, but not to anyone else.

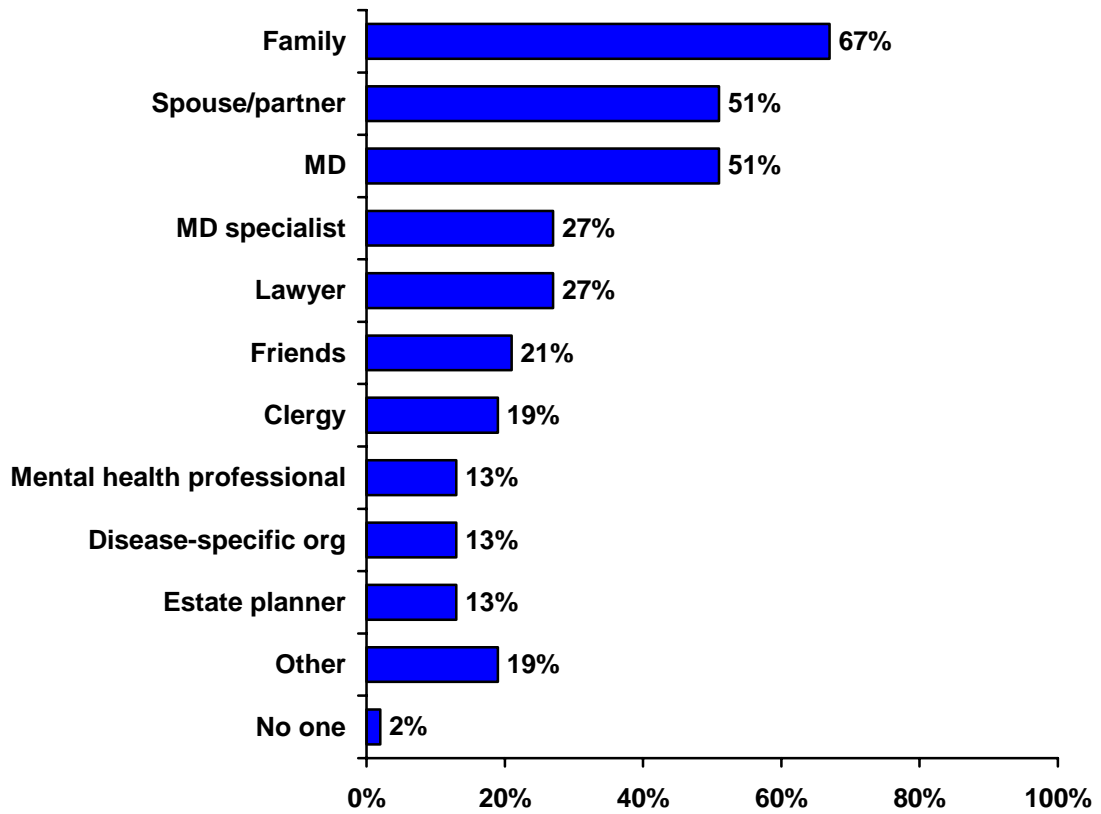
**People Talked to about End of Life Wishes
(multiple answers allowed)
(N=1,448)**



When asked who they would like to initiate a conversation with them about end of life issues, members wanted family members (73%) or a spouse or partner (57%) to begin such discussions. Four in ten (44%) wanted such a discussion initiated by a primary care physician, while a quarter (25%) wanted such a discussion with a friend. Fewer members wanted a lawyer (21%) or a clergy member (17%) to initiate such discussions.

Members were asked who they would trust to provide information on end of life issues. Most members say they would trust a family member, while half say they trust a spouse or partner or a primary care physician. Fewer members listed a lawyer, friends, or a clergy member.

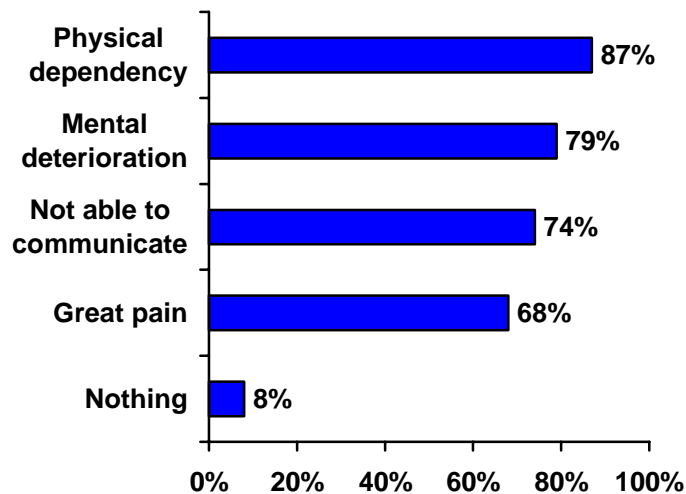
**People Trusted about End of Life Wishes
(multiple answers allowed)
(N=1,448)**



End of Life Concerns

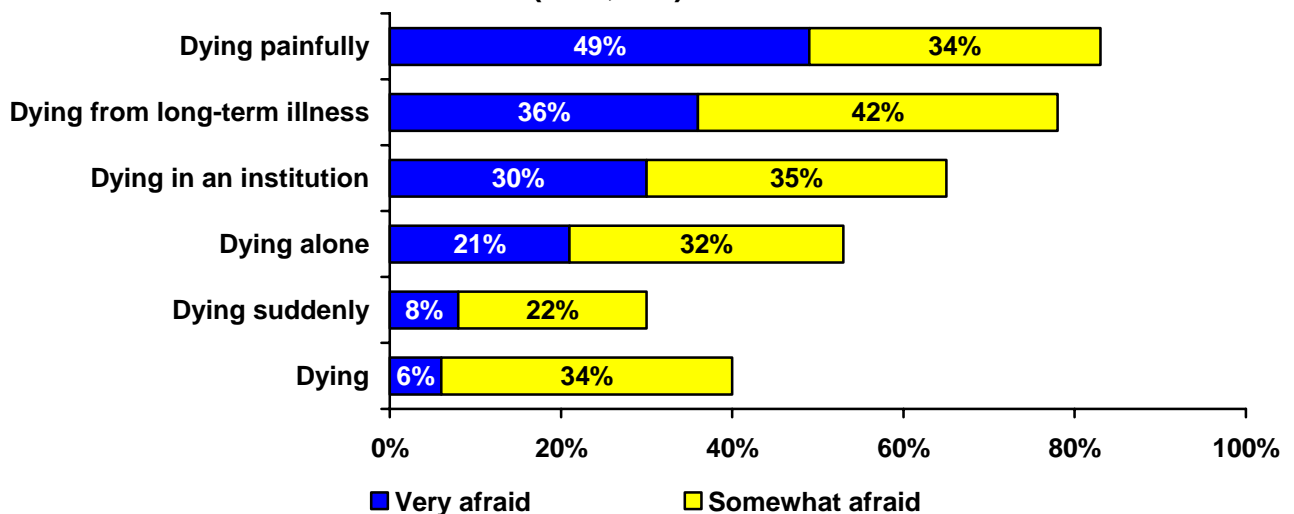
Members were asked whether certain health problems were worse than death. Eighty-seven percent say total physical dependency on others, such as being in a coma, is worse than death. For 79 percent of members, severe mental deterioration or memory loss is worse than death. Seventy-four percent indicate that not being able to communicate their wishes or needs to family and friends is worse than death, and 68 percent say that living with great pain is worse. Only eight percent say that nothing is worse than death.

Circumstances Worse than Death
(N=1,448)



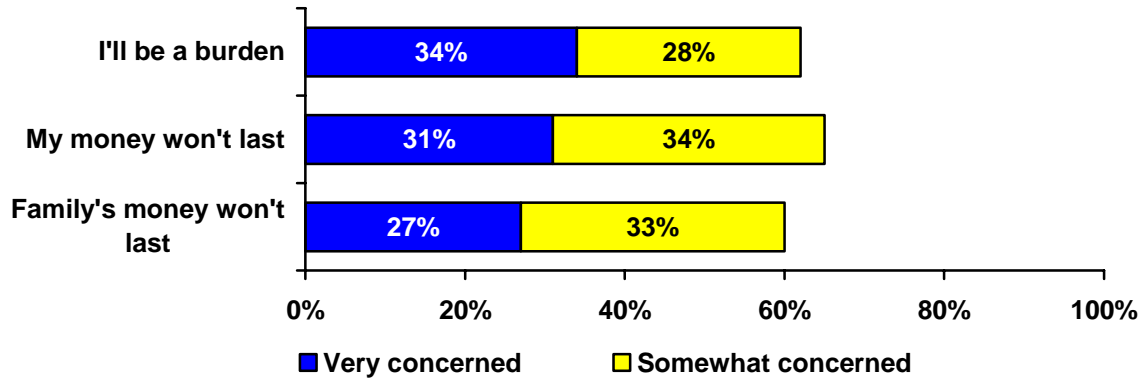
A similar picture emerges when respondents are asked how fearful they are of end of life; while four in ten fear dying; significantly more fear dying painfully, from a long-term illness, or in an institution.

Fear of Dying
(N=1,448)



Member concerns about the end of life are not limited to concerns about the process of dying. Over half of members are concerned about financial issues, such as running out of money or being a financial burden to family or friends.

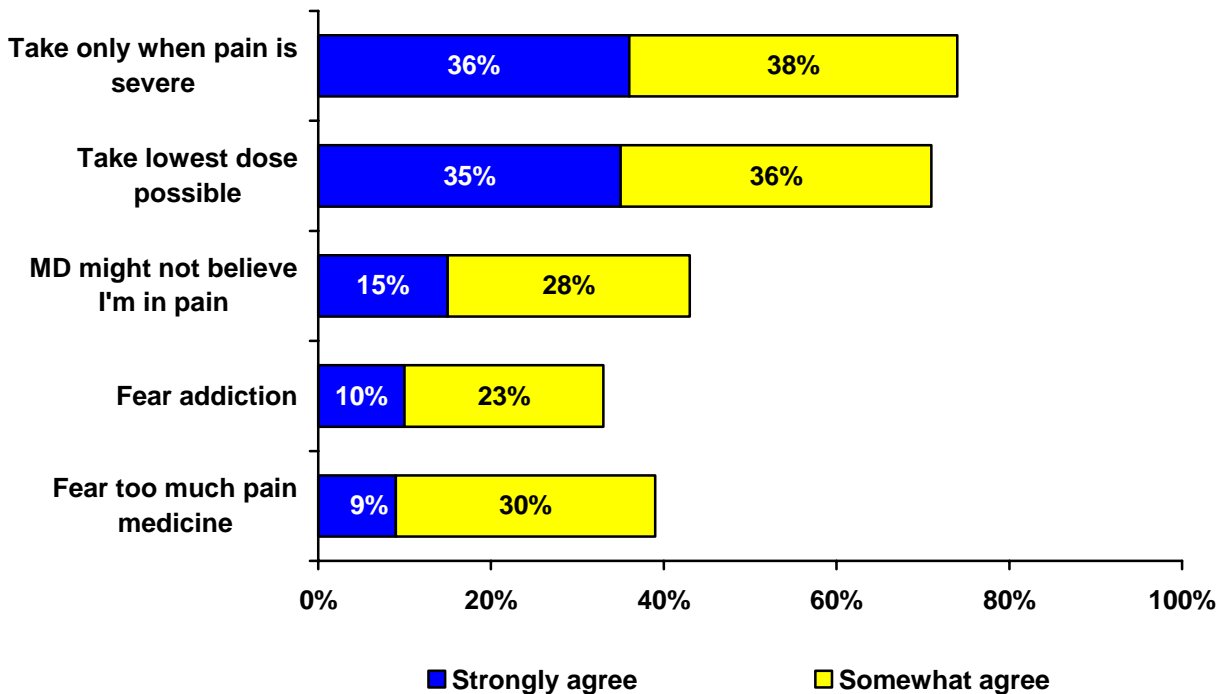
Concerns about Dying (N=1,448)



Pain Management

One of members' biggest fears, as already noted, is that of dying painfully. However, many indicate that they might restrict their pain medications. About seven in ten say that they would only take pain medication when the pain was severe, and a similar number would take low doses of pain medication to save larger doses for when the pain is worse.

Opinions on Pain Management (N=1,448)



End of Life Needs and Preferences

If they could choose where they would die, a majority of AARP members in Massachusetts say they would prefer to die at home (67%). Fewer members say they would prefer to die in a residential hospice (13%) or in a hospital (11%). One in ten stated no preference.

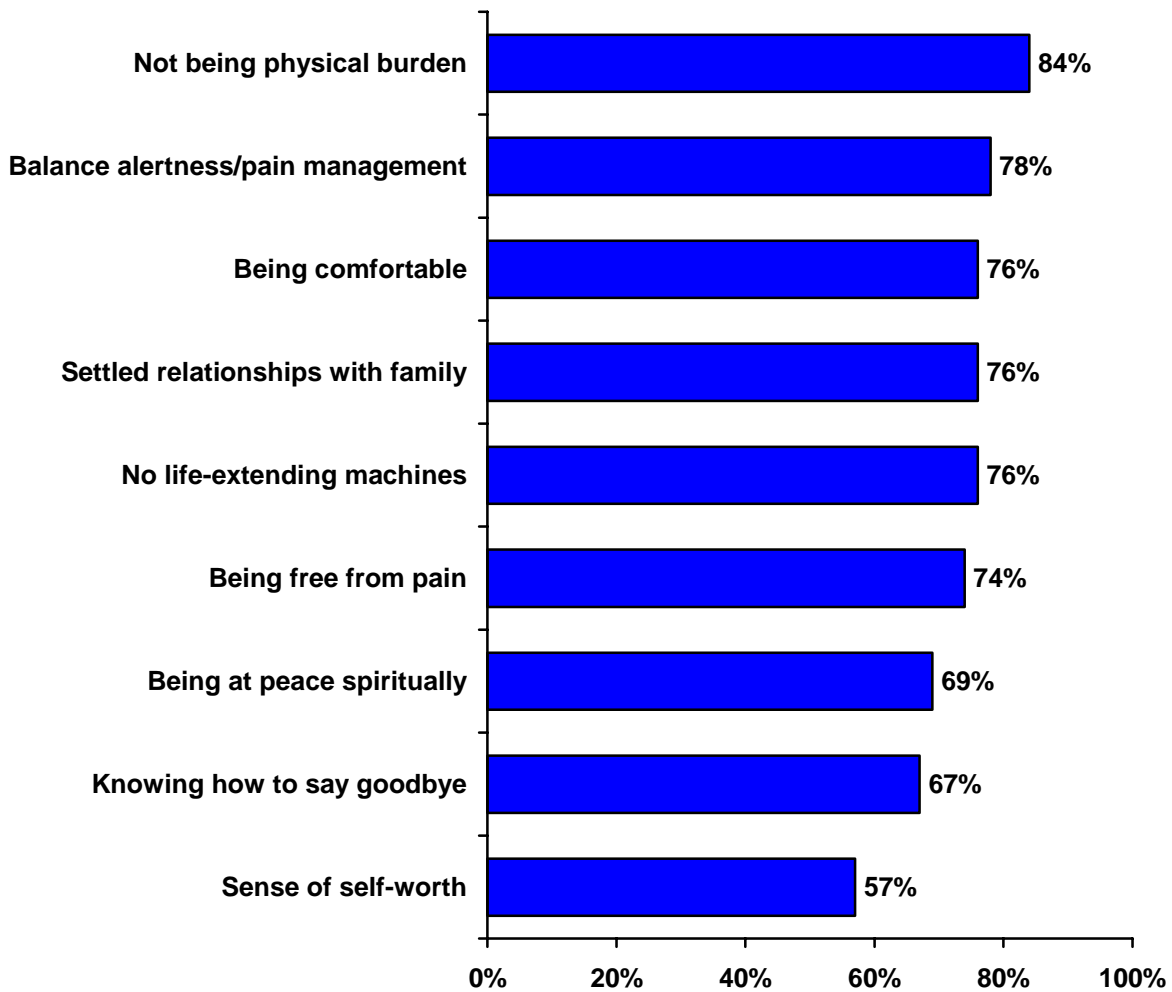
AARP Massachusetts members were asked how important various aspects of dealing with their own dying were to them. Understanding and dealing with their final illness is important to members: getting honest answers from a doctor, understanding treatment options, and having good pain management available are the top three important things for members when dealing with their own dying.

Very Important Aspects of Dealing With Your Own Dying (N=1,448)



Respondents were also asked how important a series of issues was when thinking about dying. The most often mentioned issue was not being a physical burden to others. This issue was followed by a cluster of issues mentioned by three out of four respondents. Clearly, pain management and being comfortable while dying are important issues for members. In addition, members say they want to settle their relationships with family and that they do not want life-extending machines.

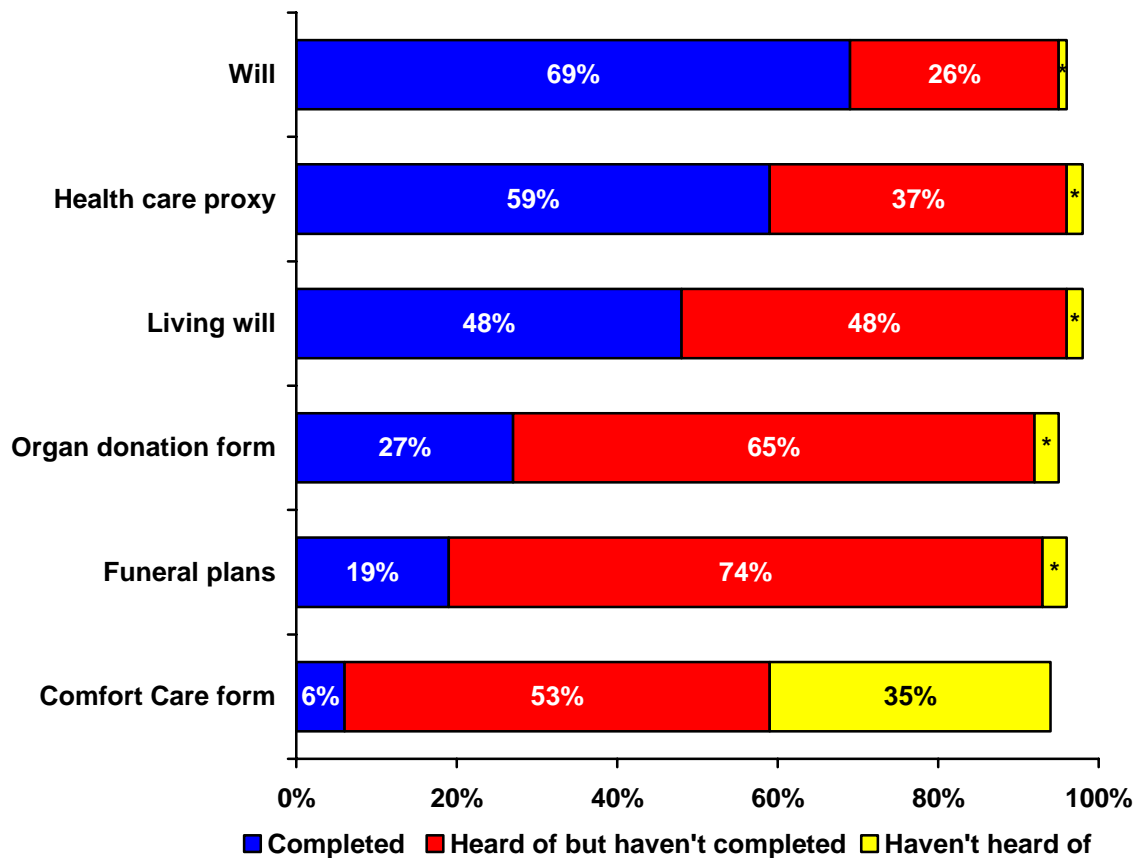
Very Important Aspects of Thinking about Dying (N=1,448)



Advance Care Planning

Although many AARP members in Massachusetts have clear end of life wishes, such as preferring to die at home, many have not translated these wishes into action through advance care planning. Many members do have a will, and six in ten have a health care proxy. However, fewer than half have a living will.² Interestingly, most members have at least heard of the advance planning tools mentioned. Although almost six in ten members say they have completed or heard about the Comfort Care form, it is possible that this number includes those who have heard about or completed a “do not resuscitate” order.³

Advance Planning and Preparation
(N=1,448)



* Less than 5%

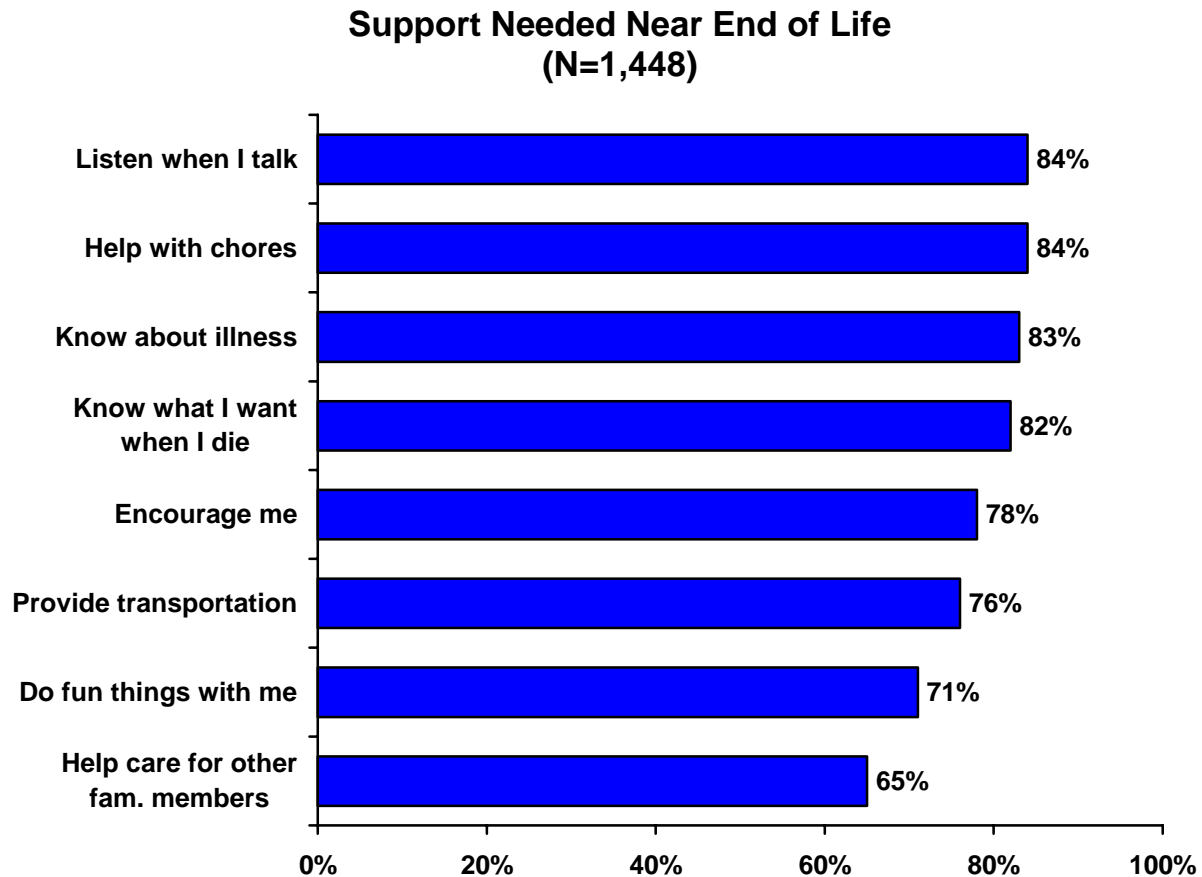
² Massachusetts does not have a statute governing the use of living wills. However, a statement such as a living will may be used as evidence of a persons' preferences for end of life care.

³ On the questionnaire, the Comfort Care form was described as “a form and bracelet to verify that you have a valid Do Not Resuscitate order and thereby authorize emergency services personnel to honor your DNR status when they are called to a non-hospital setting for emergency transport.”

Support from Others

AARP Massachusetts members were asked which types of support they expected to need near the end of their lives. Members were then asked who should provide this support.

About two-thirds expect to need each type of support mentioned in the survey at the end of their lives. Eight in ten say they need someone to listen when they talk, help with chores, and know about their illness and what they want when they die.



Members expect children and other family members and spouses/partners to provide most of the support they need. For every type of support listed, children and spouses/partners are the top support givers. However, respondents also expect to receive support from health providers, paid caregivers, and friends and neighbors. Interestingly, members expect health care providers to listen when they talk and encourage them, roles that health care providers might not normally play. Respondents are likely to rely on friends and neighbors for encouragement and to do fun things with them.

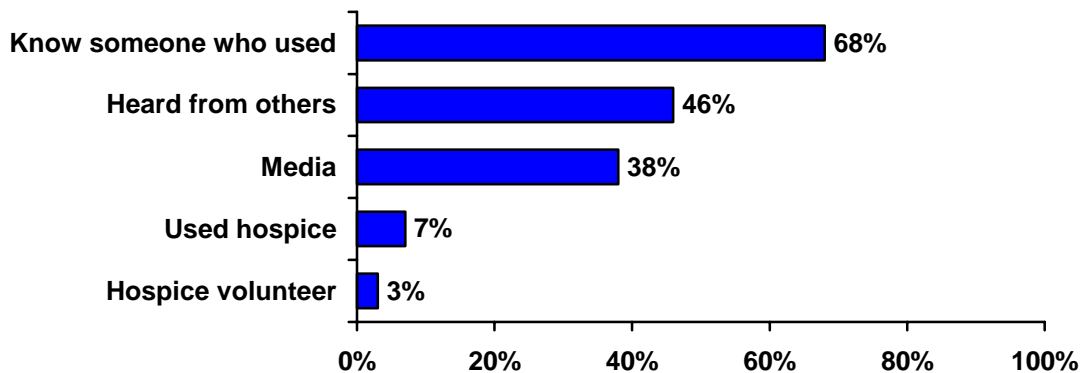
Who Should Provide Various Types of Support Among Those Who Want Each Type of Support

	Kids	Spouse/ partner	Paid care- givers	Friends/ neighbors	Faith cmty.	Health providers	Com- munity orgs.
Listen when I talk (n=1410)	86	62	30	35	22	49	6
Help with chores (n=1403)	73	57	49	26	10	23	18
Know about illness (n=1420)	83	61	30	36	19	50	8
Know what I want when I die (n=1407)	84	63	15	23	14	25	3
Encourage me (n=1374)	83	62	20	51	26	29	10
Transportation (n=1410)	79	57	32	35	13	23	26
Do fun things with me (n=1268)	84	62	10	52	11	6	9
Help care for family (n=1218)	75	53	19	27	16	17	11

Hospice Services

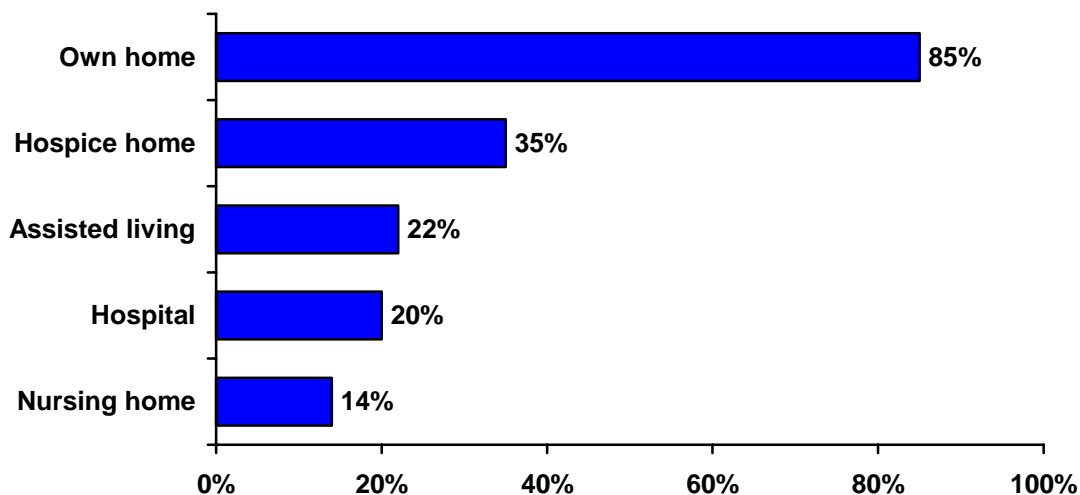
Reported awareness of hospice services is widespread, with 56 percent indicating that they have heard a lot about hospice, and another 37 percent reporting they have heard a little. Four in ten (38%) know that Medicare and Medicaid will pay for hospice service, while 36 percent did not know this. Twenty-three percent are not sure who pays for hospice. Of those who know at least a little about hospice services, most learned about it from someone who used hospice care.

How Found Out About Hospice
(n=1,406)



Three-fourths (76%) of those who have heard of hospice say they would consider using it. Most say they would like to receive hospice support in their own home, which is consistent with most members saying they would prefer to die at home.

Where Members Would Like to Receive Hospice Care
(n=1,353)



Respondent Profile

Half of the sample is female, and 44 percent of respondents are male. Four in ten (43%) are 60 to 74 years old, while 24 percent are 50 to 59 and 28 percent are 75 or older. Half (53%) are married, while 21 percent are widowed. Two in ten have a high school degree (20%), 29 percent have some college or technical education, and four in ten have a college degree (19%) or a post-graduate degree (21%). Half (51%) are retired and not working while 26 percent continue to work full-time. Nine in ten (92%) describe themselves as white and speak English as their primary language (98%). Three in ten (30%) have an annual income of under \$30,000, 35 percent have an annual income of \$30,000 to under \$75,000, and 24 percent have an income of over \$75,000. Forty-eight percent say they are affiliated with a faith community.

About half (48%) of respondents say that their health is excellent (15%) or very good (33%), while an additional 32 percent say they are in good health. Only 16 percent say they are in fair (14%) or poor (2%) health. Seven in ten say they have no serious chronic illness, while 21 percent say that they do. Seventeen percent say that someone in their household suffers from a serious chronic illness. Of these (n=341), 54 percent incur costs for medication.

The vast majority of respondents (93%) are covered by health insurance. About three in ten (28%) say that in the last year they spent less than \$50 a month out of their own pocket for doctor's visits, and a similar percentage (32%) say they spent between \$51 and \$199 a month. Two in ten (19%) spent \$200 to less than \$500, and nine percent spent over \$500 a month.

Similarly, 43 percent spent less than \$50 a month out of their own pocket last year for prescription drugs, while 38 percent spent \$51 to \$199 a month. Eleven percent say they spent over \$200 a month for prescription drugs.

Conclusions

This survey of AARP members in Massachusetts indicates that many of them have thought about and talked to their immediate family about end of life issues. Members say they are comfortable talking about death, and most are likely to attend funeral or memorial services and to visit a bereaved friend or relative. Members also say they are likely to talk to loved ones freely about death and dying. Respondents say they want a family member or spouse/partner to initiate a conversation with them regarding end of life issues.

When it comes to end of life plans and making their wishes known, Massachusetts members say they have made a will and many have a health care proxy or durable power of attorney for health care. However, they have discussed these end of life issues only with their family or spouse/partner. Only a quarter say they have discussed their wishes with a lawyer, and one in six have had this discussion with their doctor.

AARP Massachusetts members recognize that there is value in getting older, and that dying is a part of life. However, many members are concerned that they will run out of money before they die, and do not want to be a physical or financial burden to loved ones. Respondents say they also fear living with pain and not having adequate pain management. However, becoming addicted to pain medication is also a fear for respondents.

Many Massachusetts members are willing to think about and talk about end of life issues. However, they may not be having the needed discussions with health care and legal professionals who can help them make informed decisions and alleviate some of their fears.

Methodology

In March/April 2005, AARP conducted a mail survey of AARP members in Massachusetts. Each respondent was contacted four times, receiving the following pieces of mail: a pre-notification postcard, the survey, a reminder postcard, and a second survey. From a random sample of 3,000 members selected from AARP's membership database, a total of 1,448 completed surveys were returned by the cutoff date, yielding a 48 percent response rate.

The survey has a sampling error of plus or minus 1.7 percent. This means that in 95 out of 100 samples of this size, the results obtained in the sample would fall in a range of ± 1.7 percentage points of what would have been obtained if every Massachusetts member age 50 and older had been surveyed. Minor weights were applied to the survey results to reflect the distribution of age in the membership of Massachusetts. All percentages in this report and the annotated survey are based on the weighted data. The standard AARP age brackets are used when referring to age differences: 50-59, 60-74, and 75+.

For more information about this study, contact Erica Dinger, AARP Knowledge Management, at (202) 434-6176 or edinger@aarp.org.

Annotated Questionnaire

Massachusetts End of Life Survey

Weighted n = 1,448; Response Rate = 48 %; Sampling Error = +/-1.7

(Percentages may not add to 100% due to rounding or multiple responses. A “*” means less than 1%)

This survey is about end of life issues. It includes questions about your attitudes, beliefs and experiences concerning topics that may be sensitive. Your responses will help us to gain a better understanding of what is important to people in Massachusetts when they think about end of life issues. The survey should take only 20 minutes and we would really appreciate your participation.

Thoughts about Death and Dying

1. Thinking back on your childhood, how often were death and dying talked about in your family?

	<u>%</u>
Often	5
Occasionally	30
Rarely	43
Never	16
Can't remember	5
No Response	1

2. How comfortable are you with...

	Very comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable	Not sure	No Response
	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>
a. Talking about death	45	39	10	2	2	1
b. Writing your own will	65	19	7	3	2	3
c. Appointing a health care proxy to act for you if you were unable to communicate	74	16	5	2	2	2

3. How likely are you to...

	Very likely %	Somewhat likely %	Not very likely %	Not at all likely %	Not sure %	No Response %
a. Attend funerals or memorial services	56	33	7	1	*	2
b. Read books, newspaper articles or other information that deal with the subject of death and dying	29	40	21	7	1	3
c. Watch television programs or movies that deal with the subject of death and dying	19	38	30	10	1	2
d. Avoid medical checkups because you are afraid the doctor will find "something serious"	4	9	20	65	1	2
e. Speak freely to loved ones about death and dying	38	43	13	4	1	2
f. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing	47	38	10	3	1	2
g. Preplan your own funeral	33	31	17	10	4	5

4. How afraid, if at all, are you of...

	Very afraid %	Somewhat afraid %	Not very afraid %	Not at all afraid %	Not sure %	No Response %
a. Dying	6	34	28	25	5	2
b. Dying from a long-term illness	36	42	11	5	4	3
c. Dying suddenly	8	22	28	36	3	3
d. Dying alone	21	32	21	18	6	2
e. Dying in an institution such as a nursing home or hospital	30	35	18	9	6	2
f. Dying painfully	49	34	8	3	5	2

5. How strongly do you agree or disagree that...

	Strongly agree <u>%</u>	Somewhat agree <u>%</u>	Somewhat disagree <u>%</u>	Strongly disagree <u>%</u>	Not sure <u>%</u>	No Response <u>%</u>
a. There is a special value in getting old	32	40	15	7	4	2
b. Dying is an important part of life	45	34	8	5	5	2
c. You would want to know if you had a serious illness	75	17	3	1	2	2
d. You would want to know if you only had a few months to live	73	15	3	3	4	2
e. Caring for people who are dying is a rewarding experience	30	36	14	7	11	2

6. When you think about death and dying, how concerned are you that...

	Very concerned <u>%</u>	Somewhat concerned <u>%</u>	Not very concerned <u>%</u>	Not at all concerned <u>%</u>	Not sure <u>%</u>	No Response <u>%</u>
a. Your (or your spouse/partner's) money won't last	31	34	21	10	2	3
b. Your family's money won't last	27	33	22	11	3	4
c. You will be a financial burden to your family or friends	34	28	22	12	2	2

7. Which of the following health problems, if any, do you think are worse than death?
(Check ALL that apply.)

	<u>%</u>
Living with great pain	68
Total physical dependency on others, such as being in a coma	87
Not being able to communicate my wishes and/or needs to family and friends	74
Severe mental deterioration or severe memory loss	79
Nothing is worse than death	8
No Response	2

Advance Planning and Preparation

8. 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 and other pre-plans have you heard about and completed?

	Have heard about <u>and</u> completed	Have heard about but <u>not</u> completed	Have not heard about	No Response
	%	%	%	%
a. A health care proxy or durable power of attorney for health care in which you name someone to make decisions about your health care in the event you become incapacitated	59	37	2	2
b. A living will or other written instructions in which you state the kind of health care you want or don't want under certain circumstances	48	48	2	3
c. A Comfort Care form and bracelet to verify that you have a valid Do Not Resuscitate ("DNR") order and thereby authorize emergency services personnel to honor your DNR status when they are called to a non-hospital setting for emergency transport	6	53	35	5
d. A last will and testament that controls how your money and other property are to be distributed	69	26	1	4
e. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself	19	74	3	4
f. Authorization to have your organs and/or tissue donated after you die for use by others in need of transplants	27	65	3	5

9. Whether you have completed any advance directives/pre-plans or not, with whom have you talked about your wishes for care near the end of your life? (Check ALL that apply.)

	<u>%</u>
Spouse/partner	54
Family	63
Friends	26
Clergy (such as minister, rabbi, etc.)	4
Lawyer	25
Estate planner	10
Funeral director	6
Primary care physician	17
MD specialists, such as: cardiologist, oncologist	5
Mental health professional, such as: social worker, psychologist, or psychiatrist	3
Disease-specific organizations, such as: American Cancer Society, Alzheimer’s Association, American Heart Association	1
No one	10
No Response	2

10. Who would you want to initiate a conversation with you regarding end of life issues? (Check ALL that apply.)

	<u>%</u>
Spouse/partner	57
Family	73
Friends	25
Clergy (such as minister, rabbi, etc.)	17
Lawyer	21
Estate planner	12
Funeral director	9
Primary care physician	44
MD specialists, such as: cardiologist, oncologist	22
Mental health professional, such as: social worker, psychologist, or psychiatrist	10
Disease-specific organizations, such as: American Cancer Society, Alzheimer’s Association, American Heart Association	7
No one	5
No Response	3

11. Who would you trust to provide information on end of life issues? (Check ALL that apply.)

	<u>%</u>
Spouse/partner	51
Family	67
Friends	21
Clergy (such as minister, rabbi, etc.)	19
Lawyer	27
Estate planner	13
Funeral director	8
Primary care physician	51
MD specialists, such as: cardiologist, oncologist	27
Mental health professional, such as: social worker, psychologist, or psychiatrist	13
Disease-specific organizations, such as: American Cancer Society, Alzheimer's Association, American Heart Association	13
No one	2
No Response	2

Dealing with Dying

12. How important would each of the following be to you when dealing with your own dying?

	Very important <u>%</u>	Somewhat important <u>%</u>	Not very important <u>%</u>	Not at all important <u>%</u>	Not sure <u>%</u>	No Response <u>%</u>
a. Family/friends visiting you	72	18	3	1	2	4
b. Being able to stay in your home	65	24	5	1	1	4
c. Honest answers from your doctor	89	6	1	*	1	4
d. Comfort from religious/spiritual practices and/or beliefs	43	28	13	8	2	6
e. Knowing medicine was available to you	81	12	1	*	1	5
f. Planning your own funeral	34	33	17	8	3	6
g. Being able to complete your will	74	14	3	2	1	7
h. Fulfilling personal goals/pleasures	43	29	14	5	2	7
i. Reviewing your life history with your family	30	32	19	9	3	6

12. How important would each of the following be to you when dealing with your own dying?

(Continued)

	Very important %	Somewhat important %	Not very important %	Not at all important %	Not Sure %	No Response %
j. Having a good relationships with your health care providers	79	16	2	*	1	3
k. Getting your finances in order	77	16	2	1	1	3
l. Understanding your treatment options	87	8	1	*	1	3
m. Giving to others in time, gifts, or wisdom	50	33	8	2	3	4
n. Having good pain management available	83	13	1	*	1	3

13. How important is each of the following to you when you think about dying?

	Very important %	Somewhat important %	Not very important %	Not at all important %	Not sure %	No Response %
a. Being physically comfortable	76	20	1	0	1	3
b. Being free from pain	74	23	1	0	1	2
c. Having relationships settled with the family	76	16	2	1	1	4
d. Being at peace spiritually	69	18	5	3	2	3
e. Not being a physical burden to loved ones	84	13	1	*	1	2
f. Knowing how to say goodbye	67	23	4	1	2	3
g. Having a sense of your own worth	57	27	7	2	2	5
h. Being off machines that extend life such as life support	76	13	2	1	4	3
i. Being able to balance alertness and pain management	78	17	1	*	1	3

14. If you were terminally ill and could choose where to die, where would you MOST want to die?
(Check ONE answer only.)

	<u>%</u>
In your own home	67
In a nursing home	1
In a hospital	11
In an assisted living facility	2
In a residential hospice (hospice services provided by a hospice owned facility)	13
No preference	10
No Response	2

15. Below are some statements related to pain near the end of life. How strongly do you agree or disagree with each statement?

	Strongly agree <u>%</u>	Somewhat agree <u>%</u>	Somewhat disagree <u>%</u>	Strongly disagree <u>%</u>	Not sure <u>%</u>	No Response <u>%</u>
a. I am afraid my doctor may not believe I am in pain or may not treat my pain	15	28	24	23	7	4
b. I would only take pain medicines when the pain is severe	36	38	12	10	2	3
c. I am afraid I will become addicted to the pain medicines over time	10	23	23	35	6	4
d. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse	35	36	12	10	4	3
e. I am afraid I would be given too much pain medicine	9	21	30	29	7	3

Support from Others

16. When people are near the end of life, they may need support from others. Which of the following types of support do you expect to need when near the end of your life, and who should provide it to you?

a. Listen when I talk

%

84 Yes →

3 No

14 No Response

If YES, who should provide this type of support? (Check ALL that apply.)

<u>%</u>		<u>%</u>	
62	Spouse/partner	6	Community organizations
86	Children and other family	49	Health providers
30	Paid caregivers	4	Work associates
35	Friends/neighbors	22	Faith community
		2	No Response

b. Provide transportation

%

76 Yes →

3 No

22 No Response

If YES, who should provide this type of support? (Check ALL that apply.)

<u>%</u>		<u>%</u>	
57	Spouse/partner	26	Community organizations
79	Children and other family	23	Health providers
32	Paid caregivers	2	Work associates
35	Friends/neighbors	13	Faith community
		3	No Response

c. Help with chores

%

84 Yes →

3 No

13 No Response

If YES, who should provide this type of support? (Check ALL that apply.)

<u>%</u>		<u>%</u>	
57	Spouse/partner	18	Community organizations
73	Children and other family	23	Health providers
49	Paid caregivers	1	Work associates
26	Friends/neighbors	10	Faith community
		4	No Response

16. When people are near the end of life, they may need support from others. Which of the following types of support do you expect to need when near the end of your life, and who should provide it to you? **(Continued)**

d. Do fun things with me

<p><u>%</u> 71 Yes → 12 No 16 No Response</p>	<p>If YES, who should provide this type of support? (Check ALL that apply.)</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;"><u>%</u></td> <td style="width: 50%;"><u>%</u></td> </tr> <tr> <td>62 Spouse/partner</td> <td>9 Community organizations</td> </tr> <tr> <td>84 Children and other family</td> <td>6 Health providers</td> </tr> <tr> <td>10 Paid caregivers</td> <td>3 Work associates</td> </tr> <tr> <td>52 Friends/neighbors</td> <td>11 Faith community</td> </tr> <tr> <td></td> <td>6 No Response</td> </tr> </table>	<u>%</u>	<u>%</u>	62 Spouse/partner	9 Community organizations	84 Children and other family	6 Health providers	10 Paid caregivers	3 Work associates	52 Friends/neighbors	11 Faith community		6 No Response
<u>%</u>	<u>%</u>												
62 Spouse/partner	9 Community organizations												
84 Children and other family	6 Health providers												
10 Paid caregivers	3 Work associates												
52 Friends/neighbors	11 Faith community												
	6 No Response												

e. Know what I want when I die

<p><u>%</u> 82 Yes → 3 No 15 No Response</p>	<p>If YES, who should provide this type of support? (Check ALL that apply.)</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;"><u>%</u></td> <td style="width: 50%;"><u>%</u></td> </tr> <tr> <td>63 Spouse/partner</td> <td>3 Community organizations</td> </tr> <tr> <td>84 Children and other family</td> <td>25 Health providers</td> </tr> <tr> <td>15 Paid caregivers</td> <td>1 Work associates</td> </tr> <tr> <td>23 Friends/neighbors</td> <td>14 Faith community</td> </tr> <tr> <td></td> <td>4 No Response</td> </tr> </table>	<u>%</u>	<u>%</u>	63 Spouse/partner	3 Community organizations	84 Children and other family	25 Health providers	15 Paid caregivers	1 Work associates	23 Friends/neighbors	14 Faith community		4 No Response
<u>%</u>	<u>%</u>												
63 Spouse/partner	3 Community organizations												
84 Children and other family	25 Health providers												
15 Paid caregivers	1 Work associates												
23 Friends/neighbors	14 Faith community												
	4 No Response												

f. Help care for other family members

<p><u>%</u> 65 Yes → 16 No 19 No Response</p>	<p>If YES, who should provide this type of support? (Check ALL that apply.)</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;"><u>%</u></td> <td style="width: 50%;"><u>%</u></td> </tr> <tr> <td>53 Spouse/partner</td> <td>11 Community organizations</td> </tr> <tr> <td>75 Children and other family</td> <td>17 Health providers</td> </tr> <tr> <td>19 Paid caregivers</td> <td>2 Work associates</td> </tr> <tr> <td>27 Friends/neighbors</td> <td>16 Faith community</td> </tr> <tr> <td></td> <td>11 No Response</td> </tr> </table>	<u>%</u>	<u>%</u>	53 Spouse/partner	11 Community organizations	75 Children and other family	17 Health providers	19 Paid caregivers	2 Work associates	27 Friends/neighbors	16 Faith community		11 No Response
<u>%</u>	<u>%</u>												
53 Spouse/partner	11 Community organizations												
75 Children and other family	17 Health providers												
19 Paid caregivers	2 Work associates												
27 Friends/neighbors	16 Faith community												
	11 No Response												

g. Encourage me when I am down

<p><u>%</u> 78 Yes → 5 No 17 No Response</p>	<p>If YES, who should provide this type of support? (Check ALL that apply.)</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;"><u>%</u></td> <td style="width: 50%;"><u>%</u></td> </tr> <tr> <td>62 Spouse/partner</td> <td>10 Community organizations</td> </tr> <tr> <td>83 Children and other family</td> <td>29 Health providers</td> </tr> <tr> <td>20 Paid caregivers</td> <td>5 Work associates</td> </tr> <tr> <td>51 Friends/neighbors</td> <td>26 Faith community</td> </tr> <tr> <td></td> <td>5 No Response</td> </tr> </table>	<u>%</u>	<u>%</u>	62 Spouse/partner	10 Community organizations	83 Children and other family	29 Health providers	20 Paid caregivers	5 Work associates	51 Friends/neighbors	26 Faith community		5 No Response
<u>%</u>	<u>%</u>												
62 Spouse/partner	10 Community organizations												
83 Children and other family	29 Health providers												
20 Paid caregivers	5 Work associates												
51 Friends/neighbors	26 Faith community												
	5 No Response												

16. When people are near the end of life, they may need support from others. Which of the following types of support do you expect to need when near the end of your life, and who should provide it to you? (Continued)

h. Know about my illness

%
83 Yes → If YES, who should provide this type of support? (Check ALL that apply.)

2 No

15 No Response

<u>%</u>		<u>%</u>	
61	Spouse/partner	8	Community organizations
83	Children and other family	50	Health providers
30	Paid caregivers	5	Work associates
36	Friends/neighbors	19	Faith community
		5	No Response

17. Have you heard of hospice services?

	<u>%</u>
I have <u>never</u> heard of hospice service → IF NEVER, SKIP TO QUESTION 21	3
I have heard <u>a little</u> about hospice services.	37
I have heard <u>a lot</u> about hospice services.	56
No Response	4

18. How did you learn about hospice services? (Check ALL that apply.) (n=1,406)

	<u>%</u>
I know someone who used hospice services	68
I have used hospice services myself	7
I am/was a hospice volunteer	3
I read literature/newspaper/TV radio/other media	38
I heard from others	46
No Response	4

19. Would you consider using hospice support? (n=1,406)

	<u>%</u>
Yes	76
No → IF NO, SKIP TO QUESTION 21	4
Don't know/not sure	15
No Response	5

20. Where would you want to receive hospice support? (Check ALL that apply.) (n=1,353)

	<u>%</u>
In a hospice residence	35
In a hospital	20
In a nursing home	14
In a residential facility such as assisted living	22
In my own home	85
No Response	6

21. Are you aware that Medicare and Medicaid pay for hospice services?

	<u>%</u>
Yes	38
No	36
Not sure	23
No Response	3

About You

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

22. In general, how would you rate your own health right now?

	<u>%</u>
Excellent health	15
Very good health	33
Good health	32
Fair health	14
Poor health	2
No Response	4

23. Do you have a serious chronic illness?

	<u>%</u>
Yes	23
No	71
No Response	7

24. Are you currently covered by any health care insurance or program including insurance through work/retirement, the military, Medicare, Medicaid or some other government program?

	<u>%</u>
Yes	93
No	3
Not sure	*
No Response	4

25. In the last 12 months, about how much did you spend each month out of your own pocket for insurance and doctor visits?

	<u>%</u>
Less than \$50 per month	28
\$50 to less than \$200 per month	32
\$200 to less than \$500 per month	19
\$500 to less than \$1,000 per month	7
\$1,000 or more per month	2
Not sure	4
No Response	8

26. In the last 12 months, about how much did you spend each month out of your own pocket for prescription drugs?

	<u>%</u>
Less than \$50 per month	43
\$50 to less than \$200 per month	38
\$200 to less than \$500 per month	9
\$500 to less than \$1,000 per month	2
\$1,000 or more per month	*
Not sure	3
No Response	5

27. Does any member of your household have a serious chronic illness?

<u>%</u>		
17	Yes	→ If yes, are you incurring costs for: (Check All that apply.) (n=341)
76	No	
6	No Response	
		<u>%</u>
		6 Caregivers or home health aides
		54 Medicines
		38 Insurance
		11 Parking
		6 Lost wages for missing time at your work
		36 No Response

28. Who would you ask to find out whether/which end of life care services are covered by insurance or otherwise available? (Check ALL that apply.)

I would contact:

	<u>%</u>
SHINE Program – “Serving Health Information Needs of Elders”	15
Executive Office of Elder Affairs-1-800-AGE-INFO	18
Local home care agency	12
Local senior center/council on aging	25
My doctor	50
My health plan	64
Medicare	44
Medicaid	14
My friends/neighbors	16
My relatives	20
Community organizations	10
Social worker	12
Faith Community	6
Work associates	2
My employer	8
None of these	2
No Response	7

29. Are you...?

	<u>%</u>
Male	44
Female	50
No Response	6

30. What was your age at your last birthday? _____ (in years)

	<u>%</u>
50-59	24
60-74	43
75 or older	28
No Response	6

31. How many people live in your household?

	<u>%</u>
1 (Me)	30
2	48
3	10
4	5
5 or more	2
No Response	6

32. What is your current marital status?

	<u>%</u>
Single, never married	7
Married	53
Living with a partner	3
Separated	1
Divorced	10
Widowed	21
No Response	5

33. What is the highest level of education that you completed?

	<u>%</u>
Less than high school	5
High school graduate or equivalent	20
Some college or technical training beyond high school	29
College graduate (4 years)	19
Post-graduate or professional degree	21
No Response	7

34. Which of the following best describes your current employment status?

	<u>%</u>
Employed or self-employed <u>full-time</u>	26
Employed or self-employed <u>part-time</u>	12
Retired and not working	51
Other, such as homemaker	3
Unemployed and looking for work	1
No Response	6

35. Are you Hispanic or Latino?

	<u>%</u>
Yes	1
No	91
No Response	8

36. Which one or more of the following would you say is your race? (Check ALL that apply.)

	<u>%</u>
White	92
Black or African American	2
Asian	*
American Indian or Alaskan Native	1
Other	1
No Response	5

37. In what language do you prefer to read or discuss information related to death and dying?

	<u>%</u>
English	98
Spanish	0
Portuguese	*
Cape Verdean Creole	0
Haitian Creole	*
Cambodian	0
Vietnamese	0
Russian	0
Chinese	0
Other	*
No Response	2

38. What was your annual household income before taxes in 2004?

	<u>%</u>
Less than \$10,000	5
\$10,000 to under \$20,000	12
\$20,000 to under \$30,000	13
\$30,000 to under \$40,000	11
\$40,000 to under \$50,000	9
\$50,000 to under \$60,000	7
\$60,000 to under \$75,000	8
\$75,000 or more	24
No Response	12

39. Are you a member of AARP?

	<u>%</u>
Yes	98
No	1
No Response	1

40. Are you a U.S. Veteran?

	<u>%</u>
Yes	30
No	67
No Response	3

41. Are you affiliated with an organized faith community?

	<u>%</u>
Yes If yes, which one? _____	48
No	47
No Response	5

42. Have you visited the Web site and online resource guide created by the Massachusetts Commission on End of Life Care at **www.endoflifecommission.org**?

	<u>%</u>
Yes	1
No	97
No Response	3

43. What is your 5-digit zip code? (WRITE IN YOUR ZIP CODE) _____

The Massachusetts Commission on End of Life Care is a state legislative commission that was established to identify ways to improve the quality of life at the end of life. The Commission has developed a *Massachusetts Resource Guide for End of Life Services* that has been distributed to libraries, Councils on Aging and Boards of Health throughout Massachusetts. If you would like more information about the Commission or the end of life resources available in communities in Massachusetts, please go to www.endoflifecommission.org or contact the Commission at 250 Washington Street, 4th floor, Boston, MA 02108.

Thank you for completing this survey!

Appendix B

Acknowledgements

AARP would like to thank the distinguished Advisory Committee of the Massachusetts Commission on End of Life Care: Pam Albert, Director of Donor Family Services of New England Organ Bank; David Ball, Vice President of Massachusetts Extended Care Federation, Debra Banda, State Director AARP Massachusetts, Michael Banville, Director of Quality Improvement Massachusetts-ALFA, Richard Beaman Project Director for the Center for Health Policy and Research, University Massachusetts Medical School; Harris Herman, Dean, Public Health & Professional Degree Programs of Tufts University School of Medicine; Mary Lou Buyse MD, President of Massachusetts Association of Health Plans; Andrea Cohen, CEO of Houseworks; Rigney Cunningham, Executive Director of Hospice & Palliative Care Federation of Massachusetts; Marcie Freeman, Director, Outreach and Recruitment and Chair, Multicultural Coalition on Aging of Hebrew Senior Life, Research & Training Institute; Amy Goldstein, MA Pain Initiative Coordinator of American Cancer Society; Ronald Hollander, President of Massachusetts Hospital Association; David Kaufman, MD, Chief, Critical Care Medicine of St. Vincent Hospital; Leslie Kirle, Senior Director for Clinical Policy and Patient Advocacy of Massachusetts Hospital Association; Ellen Leiter, Executive Director of HealthCare Dimensions; Arlene Lowney, Executive Director of Massachusetts Compassionate Care Coalition; Jean Marchant, M.Division, Director, Office of Health Care Ministry of Roman Catholic Archdiocese of Boston; Clare D. McGorrian, Attorney and Christine McCluskey, Executive Director of Central Massachusetts Partnership to Improve Care; Pamela Meister, Assistant Attorney General Office of the Attorney General; Dolores E. Mitchell, Executive Director, Group Insurance Commission; Abraham Morse, President of Massachusetts Extended Care Federation; Anita Nasra, Assistant Director of Kit Clark Senior Services; Rev. Dr. Gordon Postill, Spiritual Counselor, Old Colony Hospice; Lucilia Prates, Director of Massachusetts Medicare & Medicaid Outreach & Education; Barbra Rabson, Executive Director of Massachusetts Health Quality Partners; Betty Anne Ritcey, Director of Service Planning and Coordination of the Executive Office of Health and Human Services; Julie Rosen, Executive Director of The Kenneth B. Schwartz Center; Craig Schneider, Manager, Medicare Financial Management Branch and Charlotte Yeh, MD, Regional Administrator for Centers for Medicare & Medicaid Services; Robert Schreiber, MD, Physician-in Chief, of Hebrew Senior Life; Brunilda Torres, Director, Office of Multicultural Health, Palmira Santos, Director, Comprehensive Cancer Control and Prevention Program, Zi Zhang, Director, Health Survey Program and Cynthia Boddie-Willis, Director Division of Community Health Promotion of the Department of Public Health; Nancy Turnbull, Executive Director of Massachusetts Medicaid Policy Institute; Carol Wogrin, Director, of Mt. Ida Center for Death Education.

AARP
Knowledge Management
For more information please contact Erica Dinger (202) 434-6176
(202) 434-6176