

THE MASSACHUSETTS COMMISSION ON END OF LIFE CARE

END-OF-LIFE CARE SURVEY

REPORT PREPARED BY

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BACKGROUND:
THE MASSACHUSETTS COMMISSION ON END OF LIFE CARE

The Massachusetts Commission on End of Life Care is a state legislative commission established in FY '01 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 near 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.

Over a year ago, the Commission launched a statewide survey project - the first attempt to gather Massachusetts-specific information about end-of-life attitudes, concerns, beliefs, needs and behaviors. In launching this statewide survey project, the Commission is addressing the need for adequate Massachusetts-specific data that can be used to drive action about end-of-life care and concerns. Collecting Massachusetts-specific data is critical to the development of appropriate public policy, to training doctors, nurses and caregivers and to creating health care delivery systems that are responsive to the needs of people living in Massachusetts. These data will also be useful to employers who are interested in assuring that their health insurance benefits foster timely and appropriate care for their employees and retirees, and to medical providers, and health insurers. Raw data will be made available to researchers so that they can follow-up with their own in-depth analyses and complementary projects.

All funding for the statewide survey project was raised through grants and other private and public contributions. A grant from Rallying Points, an initiative of The Robert Wood Johnson Foundation, permitted the Commission to engage Life's End Institute: *The Missonla Demonstration Project* for technical assistance. Partnering with AARP Massachusetts brought the project closer to reality. Dana-Farber Cancer Institute and HealthCare Dimensions Hospice became the first and most substantial contributor. The Commission greatly appreciates the very generous support it received from The Commonwealth's Group Insurance Commission and its Indemnity Plan, administered by Unicare, Hebrew Senior Life, the Massachusetts Medical Society, Partners Health Care, and Wellpoint, Inc. (Unicare).

ACKNOWLEDGEMENTS

This survey is the result of collaboration between The Massachusetts Commission for End of Life Care and Life's End Institute: *Missoula Demonstration Project*, Missoula, Montana. Special thanks go to Margaret Ann Metzger, Executive Director of the Massachusetts Commission for End of Life Care, Ruth Palombo, Chair of the Massachusetts Commission on End of Life Care and the Commission's distinguished Advisory Committee (see Appendix 1 for a complete list).

The implementation of this project was led by Barbara K. Spring, Ph.D., Director of Research and Programs at Life's End Institute: *Missoula Demonstration Project*. Data analysis and tabulation of final survey results was provided by Charles Asp, Ph.D., of Asp Consulting, LLC. Magdalena P. Sokolowski, B.A. assisted in the writing of the survey report along with survey data entry. And thanks go to Ruth V. Greeley, Executive Assistant, Life's End Institute: *Missoula Demonstration Project* for survey administration and database management.

For more information, contact Barbara K. Spring at 406.728.1613 or info@lifes-end.org.

HIGHLIGHTS

The Massachusetts Commission on End of Life Care Survey captures the concerns and attitudes toward end-of-life issues of Massachusetts residents age 35 and older. The survey was conducted in March and April of 2005. A total of 755 residents responded yielding a 25 percent response rate.

TALKING AND THINKING ABOUT DEATH

- Eighty-six percent of respondents report being very or somewhat comfortable talking about death. Almost 79 percent say they are likely to speak freely with loved ones about death and dying and 88 percent report they are very or somewhat likely to visit or telephone a friend or relative who has lost a loved one.
- Thirty-seven percent indicate they have not talked about their own wishes for care near the end of life with anyone other than their spouse/partner or other family member: 10 percent have only spoken to family members, while 15 percent indicate they have only spoken to their spouse or partner, another 12 percent report having spoken to spouse/partner and other family member, but no one else.
- Only 10 percent report having discussed their wishes for care near the end of life with a primary care physician and/or a physician specialist. Seventeen percent report they have not discussed their end-of-life care wishes with anyone.
- Eighty-three percent of respondents strongly or somewhat agree that there is a special value in getting old and 84 percent of respondents strongly or somewhat agree that dying is an important part of life.

END-OF-LIFE CONCERNS

- Respondents have a variety of fears or concerns regarding the end of life:
 - ✓ Nearly 50 percent (48%) report being somewhat or very afraid of dying.
 - ✓ More than 80 percent (82%) are at least somewhat afraid of dying from a long-term illness and 87 percent are at least somewhat afraid of dying painfully.
 - ✓ Eighty-six percent say that total physical dependency on others would be worse than death and 75 percent say not being able to communicate their wishes or needs to family would be worse than death. Similarly, 76 percent say severe mental deterioration or severe memory loss would be worse than death.
 - ✓ Eighty-three percent of survey respondents report that when they think about dying, they think it is very important not to be a physical burden on loved ones. When respondents who agreed that not being a physical burden on loved ones is somewhat important are added, the percent rises to 98.

PAIN MANAGEMENT

- While 87 percent of respondents indicate they are either very or somewhat afraid of dying painfully, there are also strong concerns about pain management practices.
 - ✓ Eighty percent of survey respondents strongly or somewhat agree they would only take pain medicine when the pain is severe.
 - ✓ Seventy-three percent of respondents strongly or somewhat agree that they would take the lowest amount of medicine possible and save larger doses for later when the pain is worse. *[Experts agree that this approach is not the most effective use of pain medication and does not produce the greatest reduction of pain.]*
 - ✓ More than one-third of respondents (35%) strongly or somewhat fear becoming addicted to pain medicine overtime.

IMPORTANT ISSUES AT THE END OF LIFE

- Survey respondents rate the following as very important when dealing with their own dying: Note that the four items selected by the highest percentages of respondents represent medical needs.
 - ✓ Honest answers from doctors (93%)
 - ✓ Understanding treatment options (87%)
 - ✓ Knowing that medicines are available (82%)
 - ✓ Having good pain management available (80%)
 - ✓ Visits from family and friends (80%)
- Respondents consider the following items very important when thinking about dying:
 - ✓ Not being a physical burden on loved ones (83%)
 - ✓ Being able to balance alertness and pain management (77%)
 - ✓ Being physically comfortable (74%)
 - ✓ Being at peace spiritually (73%)
 - ✓ Having relationships settled with family (72%)

ADVANCE CARE PLANNING

- Although 71 percent of survey respondents indicate it would be very important to be off machines that extend life such as life support and 93 percent say it is at least somewhat important to be off machines that extend life, many have not taken steps to help assure their end-of-life choices are known:
 - ✓ Though 97 percent have heard about living wills or other written instructions concerning health care choices, only 26 percent have completed one.
 - ✓ Though 95 percent have heard about documents to designate a health care proxy or durable power of attorney for health care, only 37 percent have completed one.

SUPPORT FROM OTHERS

- When asked about what kind of support they expect to need near the end of life, survey respondents chose the following:
 - ✓ Listen to them (97%)
 - ✓ Know what they want when they die (96%)
 - ✓ Know about their illness (96%)
 - ✓ Help with chores (95%)
 - ✓ Provide transportation (94%)
 - ✓ Provide encouragement when they are down (92%)
 - ✓ Do fun things with them (89%)
 - ✓ Help care for other relatives (84%)

- More than three-quarters expect their children and other family members to provide each type of support and almost as many expect their spouse/partner to provide these types of support as well. Many expect support from others, including friends, faith communities, paid caregivers, neighbors and health providers.

HOSPICE SERVICES

- Only 6 percent of survey respondents have never heard of hospice, and 55 percent report they have heard a lot about hospice, yet only 33 percent are aware that Medicare & Medicaid pay for hospice services.

- The majority of respondents (69%) who had heard of hospice learned about it from knowing someone who used hospice services.

- Of those who had heard of hospice services, 79 percent would consider using hospice support.

DETAILED FINDINGS

TALKING AND THINKING ABOUT DEATH

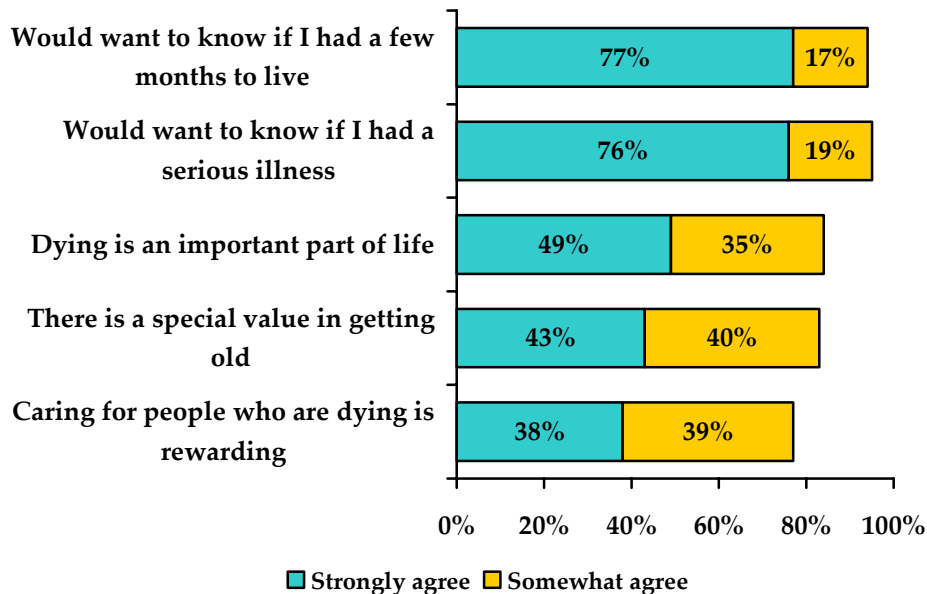
Most respondents report that during their childhood their families rarely (46%) or never (14%) talked about death and dying. Almost one-third (32%) say their families had such discussions occasionally, while only 8 percent talked about death and dying often.

Nonetheless, most respondents say they are at least somewhat comfortable talking about death (44% are very comfortable and 42% are somewhat comfortable). The majority report being very comfortable writing a will (56% are very comfortable and 29% are somewhat comfortable); similarly, the majority are comfortable with appointing a health care proxy to speak for them in the event they become unable to communicate (63% are very comfortable and 24% are somewhat comfortable).

Dying is considered an important part of life by 84 percent of respondents. Similarly, 83 percent report that there is a special value in getting old. Seventy-seven percent of respondents strongly or somewhat agree that caring for people who are dying is a rewarding experience.

An overwhelming number of respondents strongly or somewhat agree that they would want to know if they had a serious illness (95%) or only had a few months to live (94%).

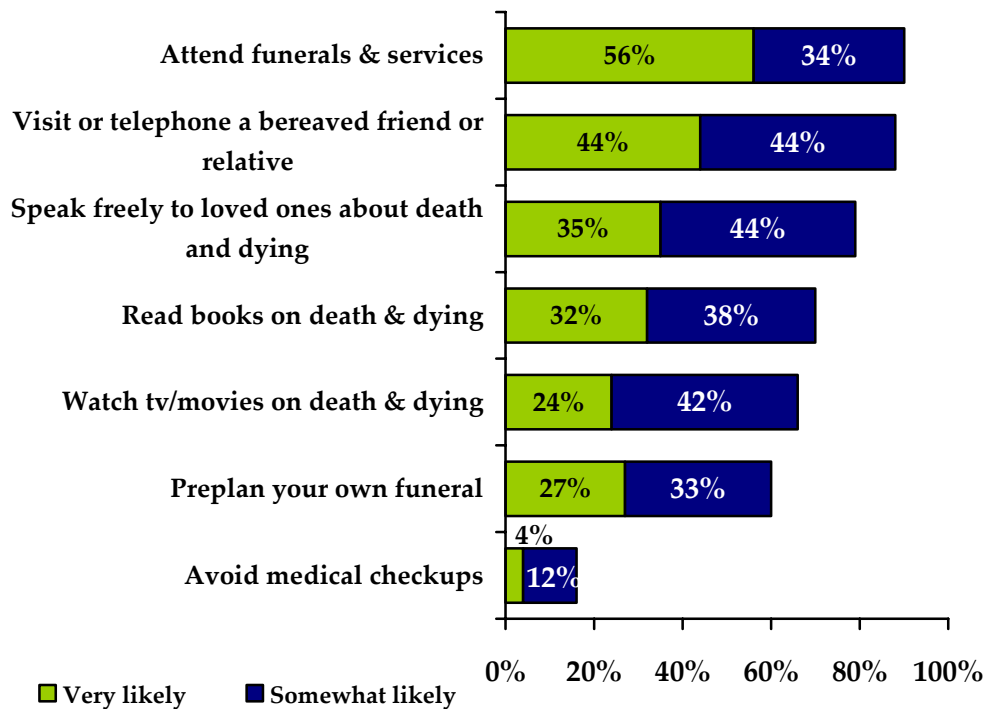
OPINIONS ON DYING N = 755



The survey asked respondents to gage their likeliness to engage in a wide range of actions or events related to death and dying.

- When a death occurs, the vast majority of respondents say that they are somewhat likely or very likely to attend funerals or memorial services (90%) and to visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing (88%).
- More than two-thirds of respondents (70%) are somewhat likely or very likely to read books, newspaper articles or other information that deal with the subject of death and dying. Similarly, 66 percent of respondents report they are somewhat likely or very likely to watch television programs or movies that deal with the subject of death and dying.
- Few respondents (16%) are very likely or somewhat likely to avoid medical checkups due to fear that the doctor will find something serious.

**LIKELIHOOD OF TAKING ACTIONS RELATED
TO DEATH AND DYING**
N = 755

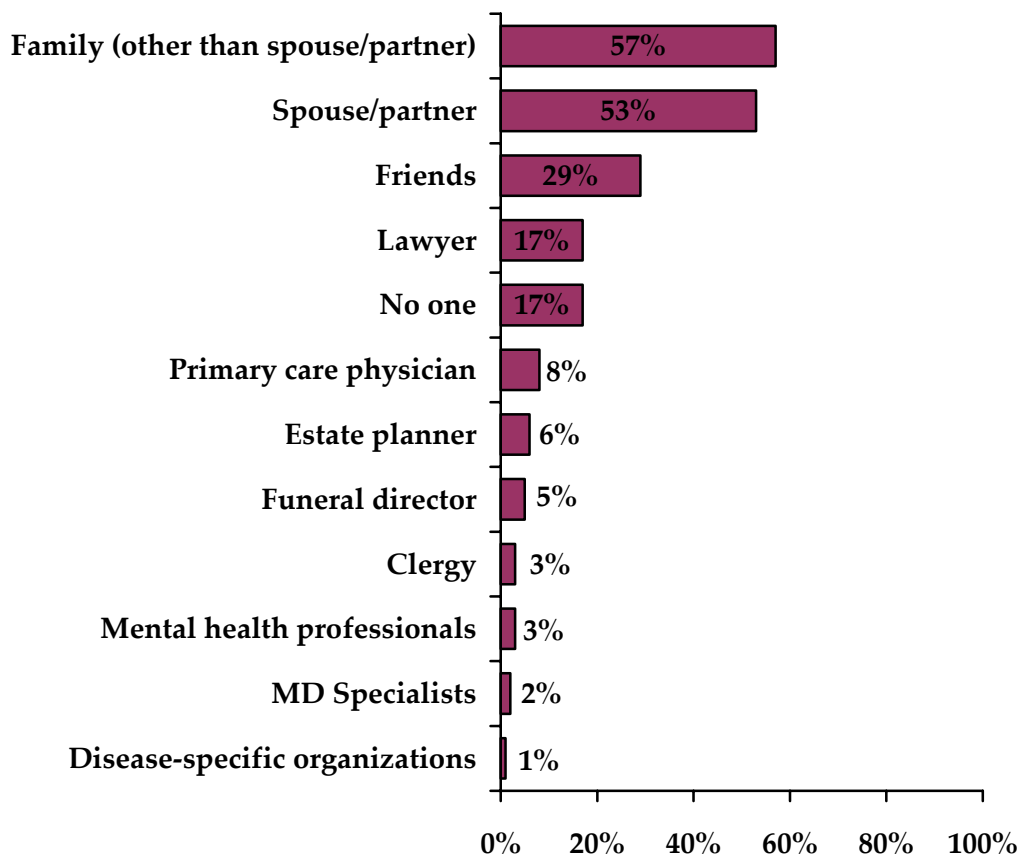


Although 86 percent report being at least somewhat comfortable talking about, family members are the only people with whom many respondents have spoken about their own end-of-life wishes.

Analysis of the data shows that 57 percent of respondents have talked to family members about their wishes for care near the end of life, 53 percent have talked with their spouse/partner and 29 percent have talked with friends, yet only 8 percent have spoken with their primary care physician and only 2 percent with any physician specialist.

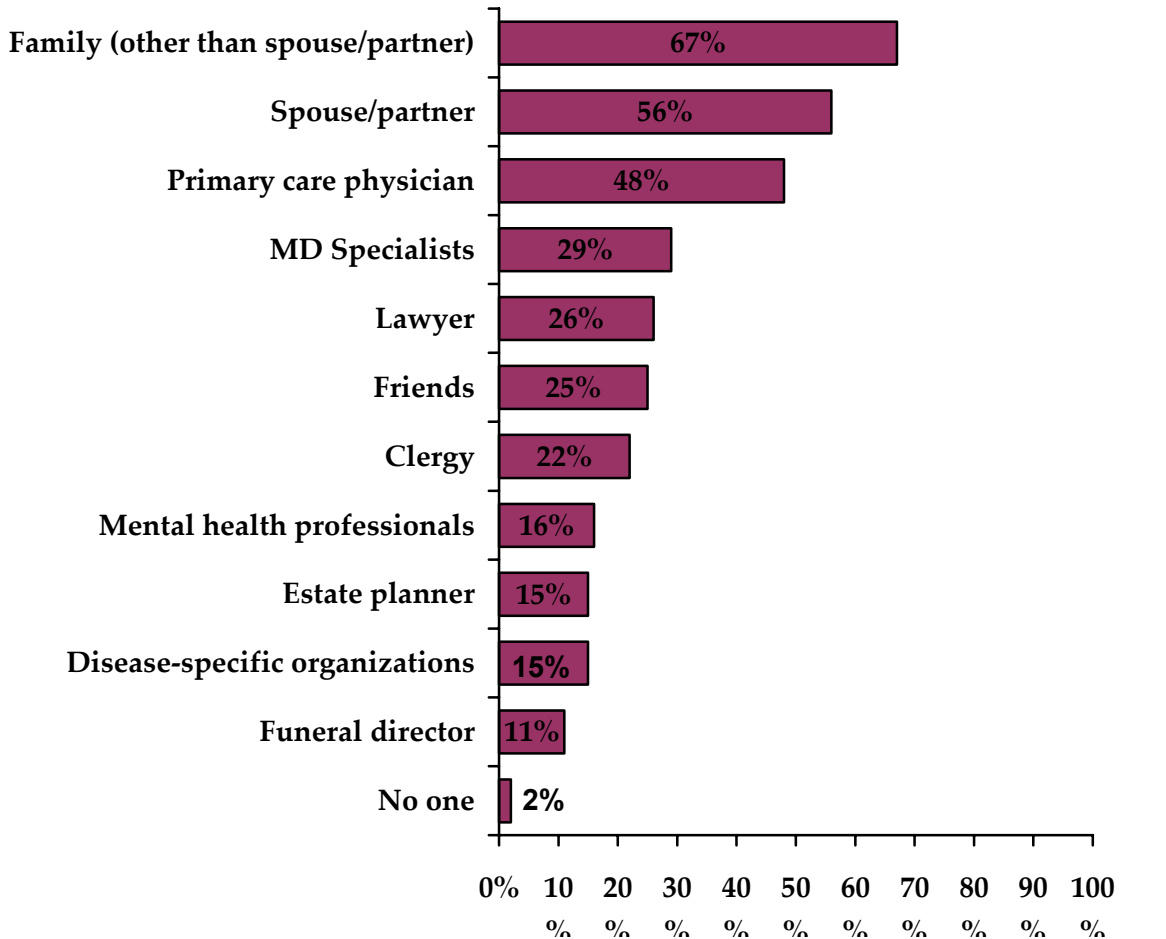
Nearly one-fifth (17%) of the respondents report they have not talked with anyone about their wishes for care near the end of life.

WHO RESPONDENTS HAVE TALKED TO ABOUT END-OF-LIFE WISHES
(MULTIPLE ANSWERS ALLOWED)
N = 755



When asked who they would trust to provide information on end-of-life issues, a majority of respondents chose family (67%) and spouse/partner (56%). Nearly half (48%) trust their primary care physician to provide information on end-of-life issues and 29 percent would trust medical specialists. Around a quarter of respondents would trust a lawyer (26%), friends (25%), or clergy (22%) to provide end-of-life related information.

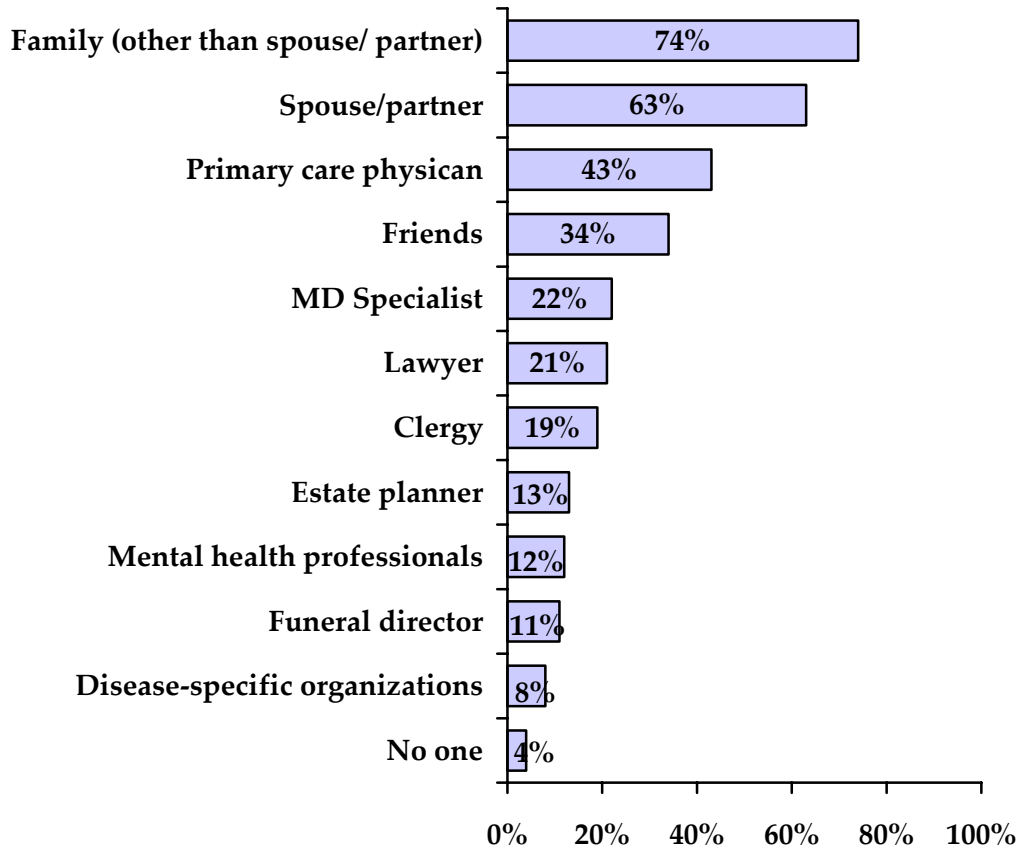
WHO RESPONDENTS WOULD TRUST TO PROVIDE INFORMATION ON END-OF-LIFE ISSUES
(MULTIPLE ANSWERS ALLOWED)
N = 755



When asked who they would want to initiate a conversation about end-of-life issues, almost three-quarters of respondents (74%) report they would want a family member to initiate such a conversation and 63 percent would want their spouse or partner to do so. Forty-three percent indicate they would want their primary care physician to initiate a conversation regarding end-of-life issues. More than one-third (34%) would like their friends to begin a conversation with them about end-of-life subjects.

**WHO RESPONDENTS WOULD WANT TO INITIATE A
CONVERSATION ABOUT END-OF-LIFE WISHES
(MULTIPLE ANSWERS ALLOWED)**

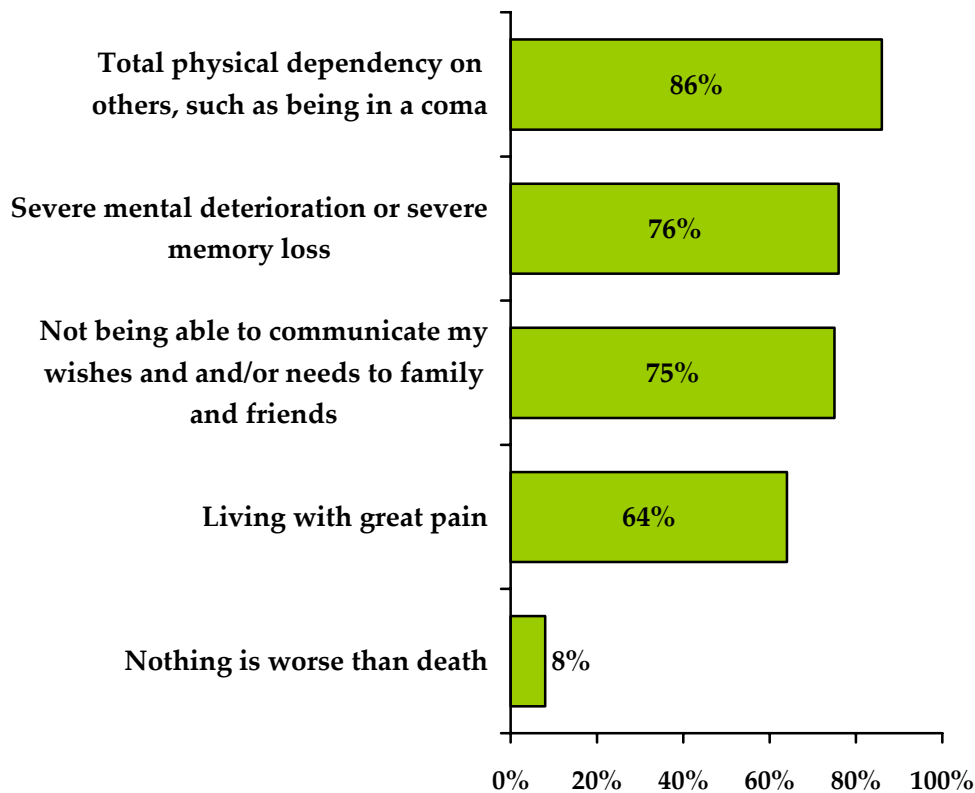
N = 755



END-OF-LIFE CONCERNS

Survey recipients were asked a series of questions regarding whether or not they consider certain health conditions worse than death. Eighty-six percent of respondents say total physical dependency on others, such as being in a coma, is worse than death. Seventy-six percent say severe mental deterioration or severe memory loss is worse than death. Seventy-five percent indicate that not being able to communicate their wishes or needs to family and friends is worse than death and 64 percent respond that living with great pain is worse. Only 8 percent say that nothing is worse than death.

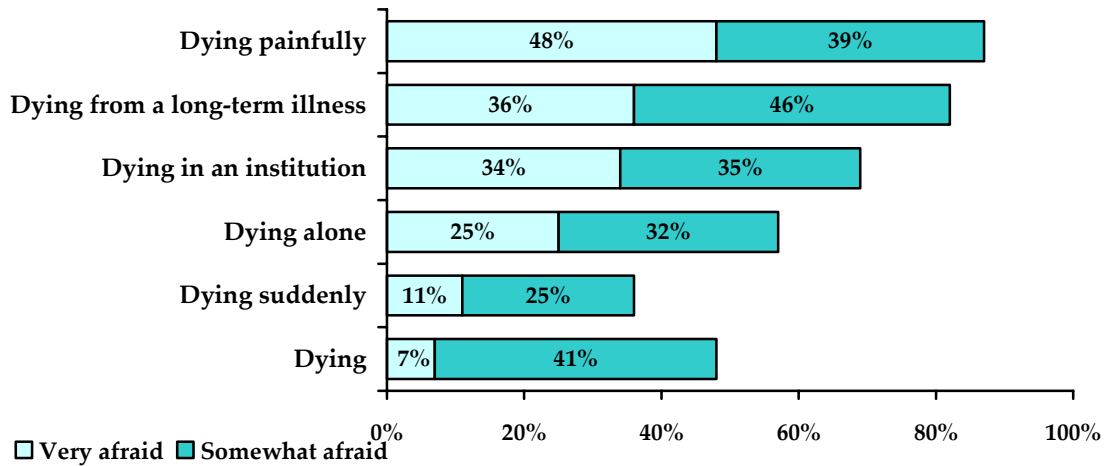
WHICH OF THE FOLLOWING HEALTH PROBLEMS, IF ANY, ARE WORSE THAN DEATH
N = 755



Responses to the question regarding which health conditions, if any, are worse than death roughly correspond to certain fears respondents have regarding dying. Eighty-seven percent of respondents report being very or somewhat afraid of dying painfully; 82 percent are at least somewhat afraid of dying from a long-term illness and more than two-thirds (69%) fear dying in an institution such as a nursing home or hospital. In contrast, only 36 percent fear dying suddenly.

RESPONDENTS' FEARS ABOUT DYING

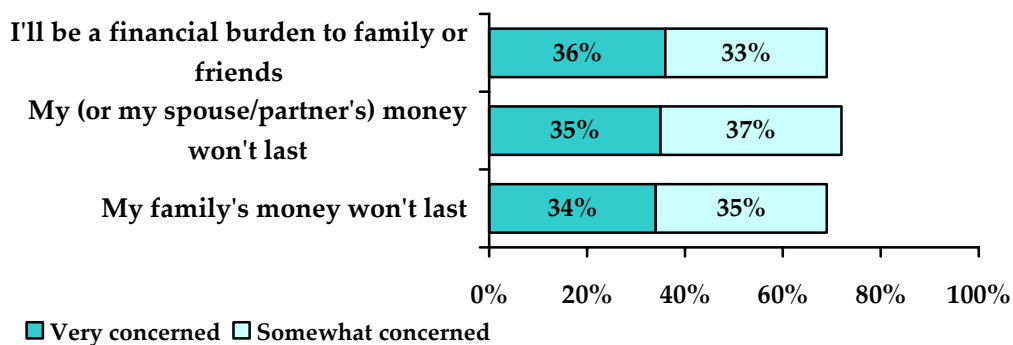
N = 755



Respondent concerns about the end of life are not limited to those associated with the physical process of dying, but include: being a financial burden on family and friends and, simply, having money sufficient to last through the dying process. Sixty-nine percent of respondents indicate they are somewhat or very concerned that they will be a financial burden to their family and friends. Seventy-two percent are concerned that their (or their spouse/partner's) money will not last and 69 percent are at least somewhat concerned that their family's money will not last.

RESPONDENTS' CONCERNS WHEN THINKING ABOUT DEATH AND DYING

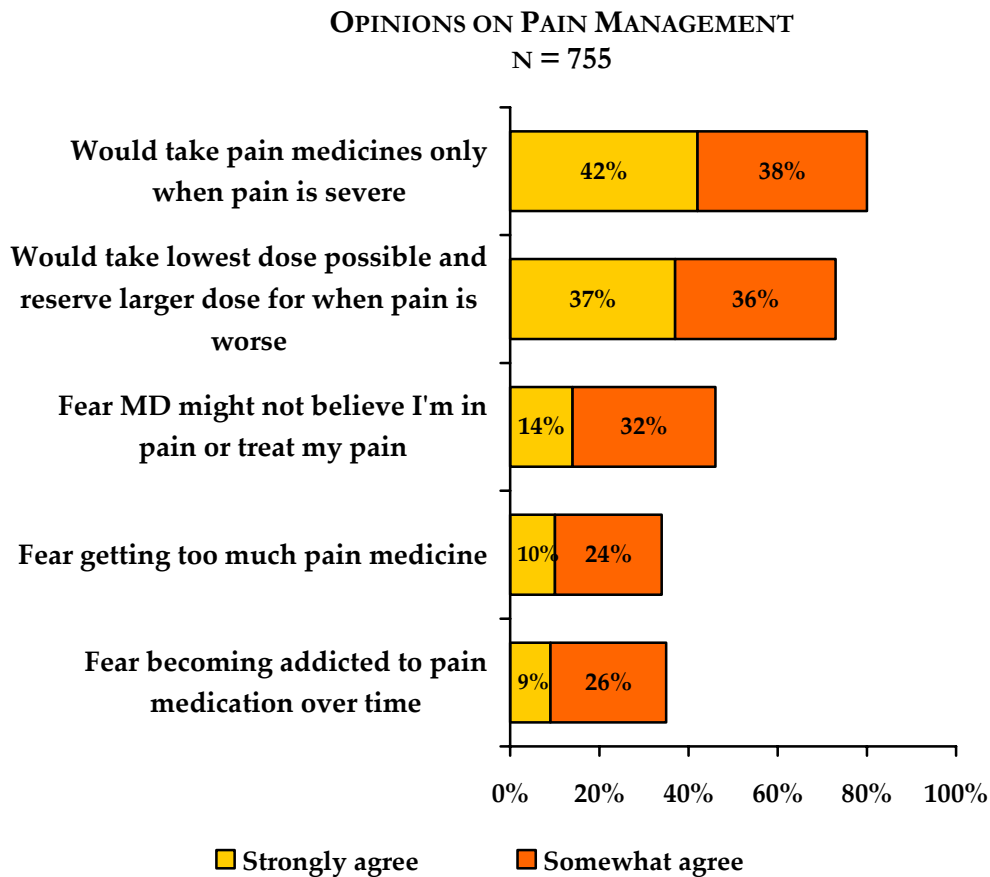
N = 755



PAIN MANAGEMENT

Eighty-seven percent of respondents say they are very to somewhat afraid of dying painfully. Yet, many indicate that they might restrict their pain medications or reserve medication use to times when pain is severe. *[Experts agree that this approach is not the most effective use of pain medication and does not produce the greatest reduction of pain.]*

- Eighty percent report that they would only take medication when the pain is severe.
- Seventy-three percent say that they would take the lowest dose of medicine possible in order to save larger doses for later when the pain is worse.
- Forty-six percent fear their physician will not believe they are in pain or may not treat their pain.
- More than one-third of respondents fear becoming addicted to pain medications overtime (35%) and fear they would be given too much pain medicine (34%).



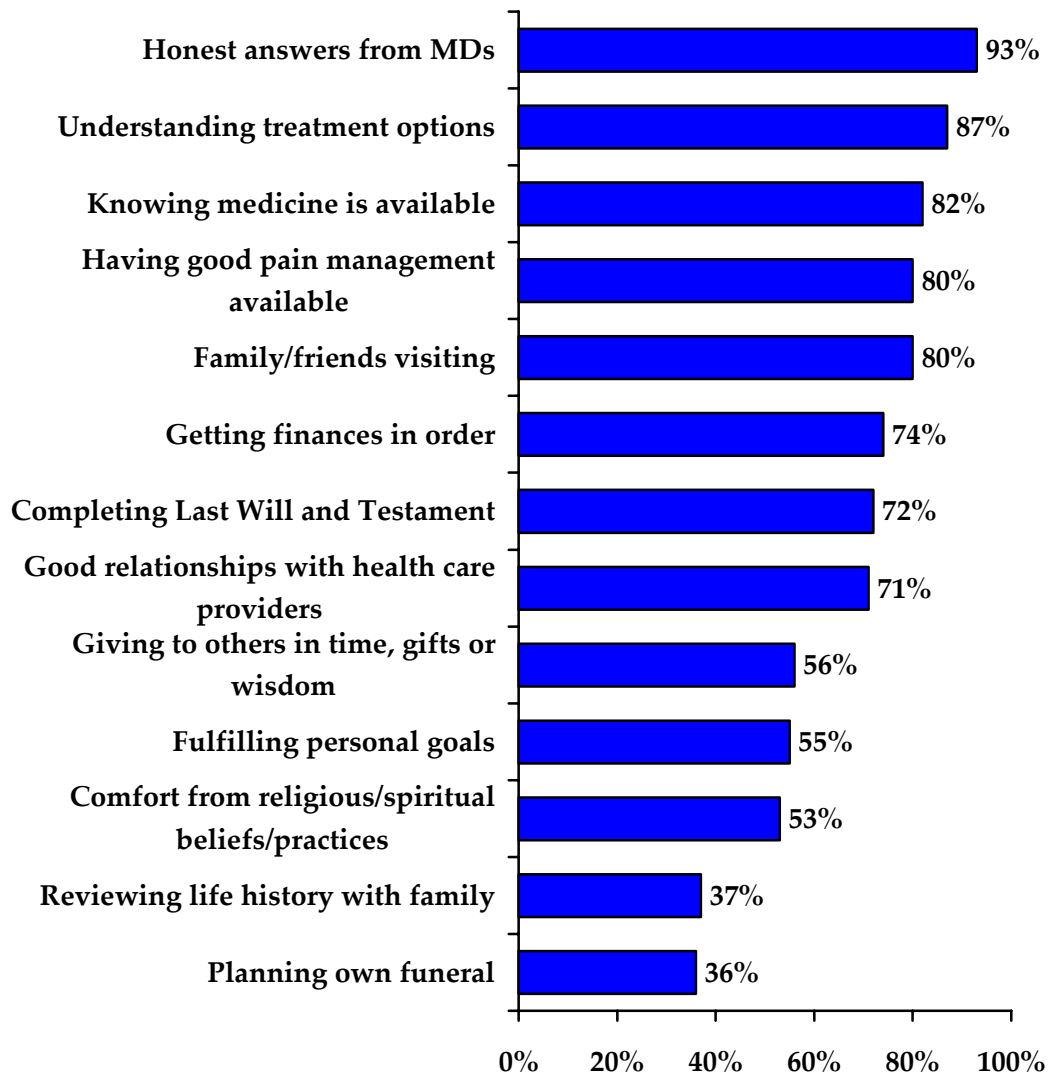
END-OF-LIFE NEEDS AND PREFERENCES

Sixty-eight percent of respondents want to die in their own home as compared to 9 percent who want to die in a hospital, 9 percent who want to die in a residential hospice, 2 percent who want to die in an assisted living home, and 1 percent who want to die in a nursing home. Twelve percent of respondents report they have no preference regarding the location of their death.

The survey also asked recipients to consider how important certain items would be to them when dealing with their own dying or when thinking about dying.

- When dealing with their own dying, most respondents consider the medical aspects of dying to be very important. Ninety-three percent say that honest answers from their doctors would be very important to them. Eighty-seven percent consider it very important to understand their treatment options, 82 percent say it would be very important to know medicine was available to them, and 80 percent consider it very important to have good pain management available. Seventy-one percent consider having good relationships with their health care providers as very important.
- Nearly three-quarters of respondents (73%) report that being at peace spiritually is very important to them when they think about dying.

VERY IMPORTANT ASPECTS OF DEALING WITH YOUR OWN DYING
N = 755



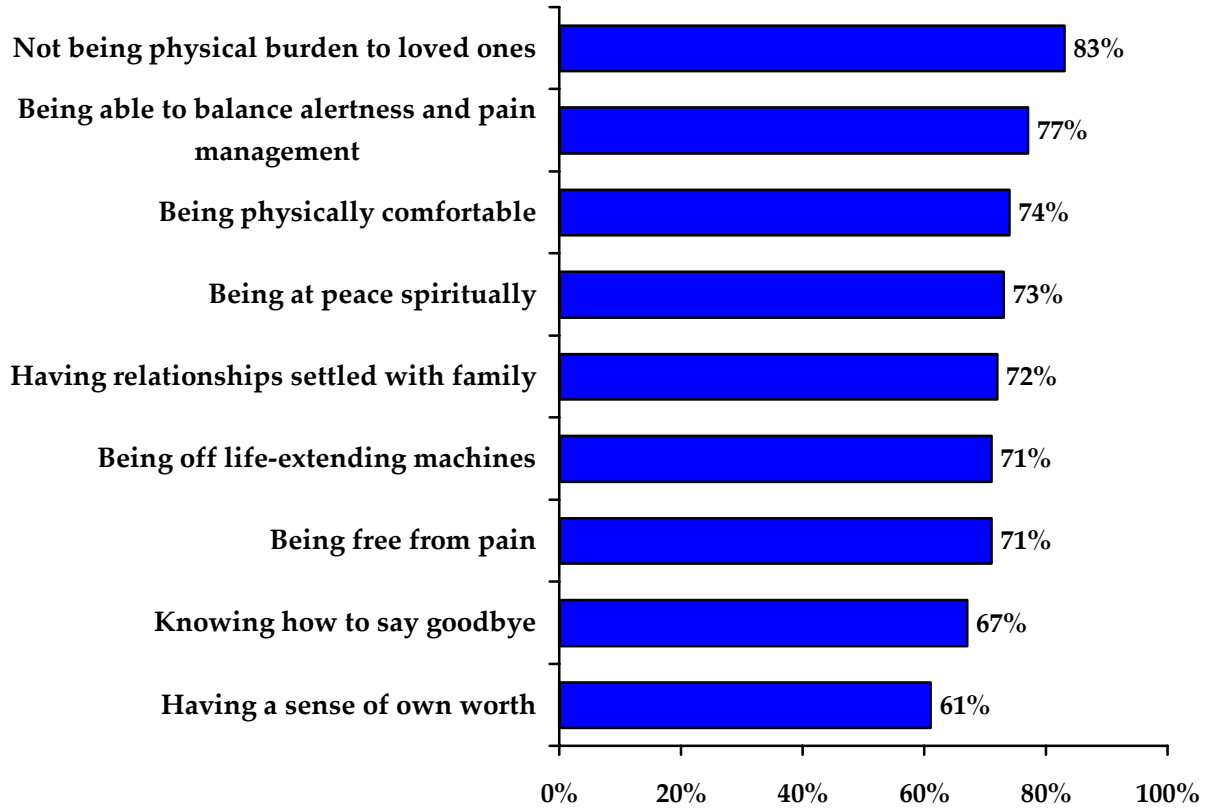
Other issues are also considered very important to a majority of respondents, including:

- Sixty-six percent of respondents say that being able to stay in their own home is very important to them when considering their own dying.
- When thinking about dying, 67 percent of respondents say it is very important to know how to say goodbye to loved ones.
- Slightly more than half (53%) of the respondents say that comfort from religious/spiritual practices and/or beliefs is very important.

- Regarding a sense of self, slightly more than six out of ten respondents (61%) say it is very important to have a sense of their own worth when thinking about dying. Slightly fewer report it is very important to give to others in time, gifts and wisdom (56%) and to fulfill personal goals/pleasures (55%) when dealing with their own dying.

VERY IMPORTANT ASPECTS OF THINKING ABOUT DYING

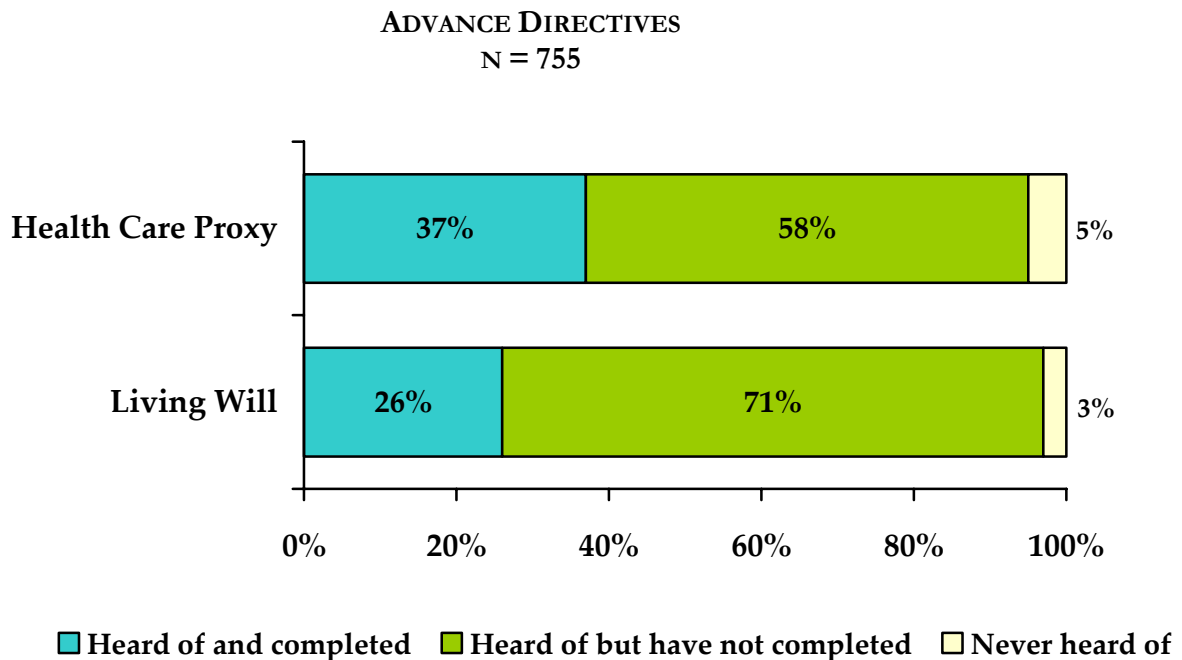
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ADVANCE CARE PLANNING

As noted earlier, many respondents have clear end-of-life care wishes. For example, 71 percent say it is very important to be off of machines that extend life, such as life support, while 93 percent say it is at least somewhat important to be off machines that extend life. But, many have not completed advance directives for health care to help ensure that their wishes are known.

- Less than one third of respondents (26%) say they have completed a living will and 37 percent have completed designating a health care power of attorney.
- Seventy-one percent of respondents report that though they have heard about a living will, they have not completed one. Similarly, 58 percent of respondents report that though they have heard about designating a health care proxy, they have not done so.

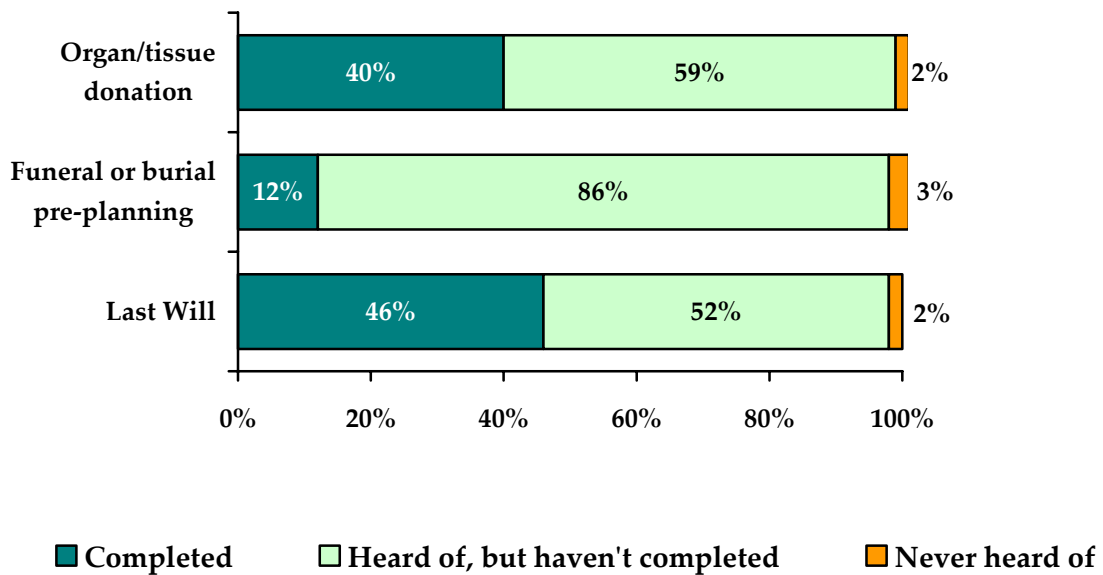


The survey also included other aspects of advance planning, such as executing a Last Will and Testament, authorizing a Comfort Care form, registering to donate organs and tissue, and completing funeral and burial pre-plans including purchasing in advance goods or services one will need.

- Though 72 percent of respondents say that being able to complete a Last Will and Testament is very important when dealing with their own dying, and 85 percent indicate they are at least somewhat comfortable with writing their own will, fewer than half (46%) have completed one.

- Seventy-two percent of respondents indicate that planning their own funeral is at least somewhat important to them when dealing with their own dying and 60 percent say that they are at least somewhat likely to preplan their funeral, yet only 12 percent report that they have actually done so.
- Four in ten respondents (40%) have completed authorization to have their organs and/or tissue donated after they die for use by others in need of transplants.

**WILLS, FUNERAL/BURIAL PRE-PLANNING
AND ORGAN/TISSUE DONATION**
N = 755

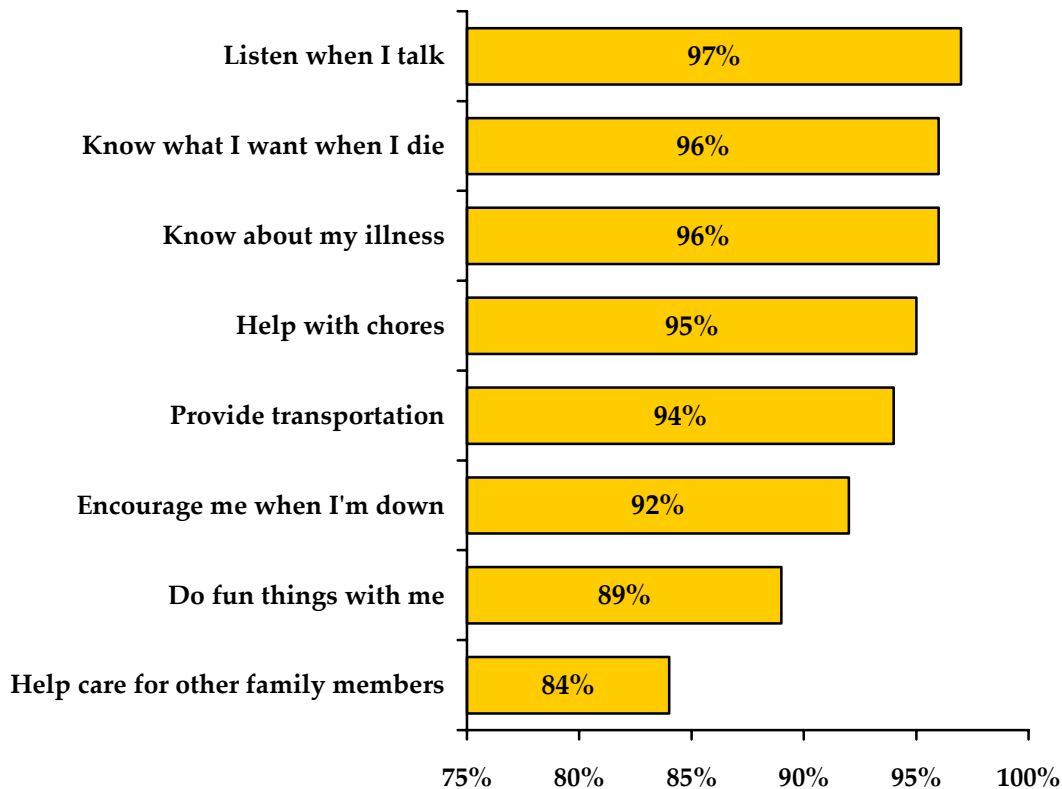


SUPPORT FROM OTHERS

The survey listed eight types of support and directed respondents to select all those they expected to need near the end of their lives. These support items ranged from practical support such as help with chores to personal support such as listening and encouragement. For each type of support selected, respondents were asked to indicate who should provide it, checking all that apply. The categories of possible providers of this support included spouse/partner, children and other family, paid caregivers, friends/neighbors, community organizations, health providers, work associates, faith community.

Sizeable majorities of respondents expect to need each type of support near the end of life.

SUPPORT THAT RESPONDENTS EXPECT TO NEED NEAR END OF LIFE N = 755



- The vast majority of respondents expect each type of support from their immediate family including their spouse or partner and/or children and other family. In each area of support, no fewer than 64 percent expect support from their spouse or partner and no fewer than 78 percent expect support from their children and other family members.

- Beyond support from immediate family, respondents typically expect their friends or neighbors to provide most types of support. The largest expectation of support from friends or neighbors support was for them to “do fun things with me” (66%).
- At least half of the respondents say that health care providers should support them by listening to them when they talk (52%) and knowing about their illness (55%). One-third (33%) expect their health care providers to encourage them when they are down.
- More than one-third of respondents expect paid caregivers to listen when they talk (33%), provide transportation (38%), help with chores (47%), and know about their illness (34%).
- More than one-quarter expect support from faith communities in the way of being listened to (27%), being encouraged when down (35%) and knowing about their illness (26%).
- In all areas, few indicate that they expect support from work associates.

WHO SHOULD PROVIDE VARIOUS TYPES OF SUPPORT (%)
(MULTIPLE RESPONSES ALLOWED)

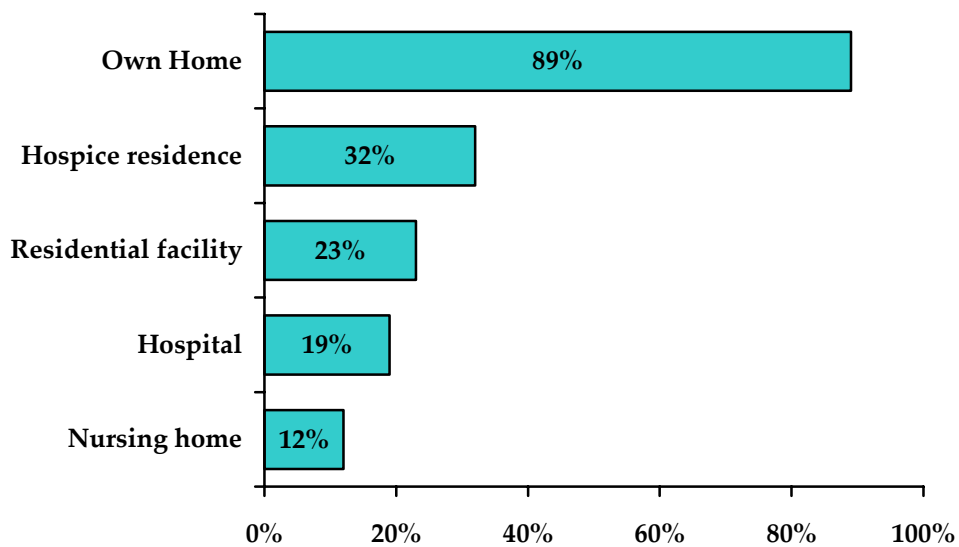
	Spouse/ Partner	Children & other family	Paid Caregivers	Friends/ Neighbors	Community organizations	Health Providers	Work Associates	Faith Community
Listen when I talk (n=753)	75%	88%	33%	44%	8%	52%	9%	27%
Transportation (n=736)	67%	80%	38%	39%	28%	23%	5%	16%
Know about my illness (n=735)	73%	88%	34%	49%	8%	55%	13%	26%
Know what I want when I die (n=737)	74%	89%	17%	32%	4%	29%	3%	17%
Help with chores (n=734)	69%	78%	47%	33%	17%	16%	3%	11%
Encourage me when I'm down (n=713)	74%	88%	21%	59%	12%	33%	13%	35%
Do fun things with me (n=677)	76%	90%	12%	66%	11%	5%	7%	15%
Help care for my family (n=626)	64%	83%	21%	38%	18%	23%	4%	22%

HOSPICE SERVICES

Most respondents report that they have heard of hospice services. More than half indicate that they have heard a lot about hospice services (55%) and an additional 39 percent have heard a little, only 6 percent report that they have never heard of hospice services.

- Yet, only 33 percent report being aware that Medicare & Medicaid pay for hospice services.
- Of those respondents who have heard of hospice, 69 percent say that they learned about it from knowing someone who has used hospice services. Forty-three percent say they heard about it from others. Nearly one-third (32%) indicate that they learned about hospice through the media and/or literature. Fewer respondents indicate having learned about hospice from other sources such as health care professionals (23%), personal experience using hospice (7%) or being a hospice volunteer (1%).
- Seventy-nine percent of those who have heard of hospice report that they would consider using hospice support. When asked where they would want to receive hospice support, 89 percent indicate that they would want it in their own home. Comparatively, 32 percent would want support in a hospice residence, 23 percent in a residential facility such as assisted living, 19 percent in a hospital, and 12 percent in a nursing home.

**WHERE RESPONDENTS WOULD WANT HOSPICE SUPPORT
(MULTIPLE ANSWERS ALLOWED)
N = 560 WHO WOULD CONSIDER USING HOSPICE**



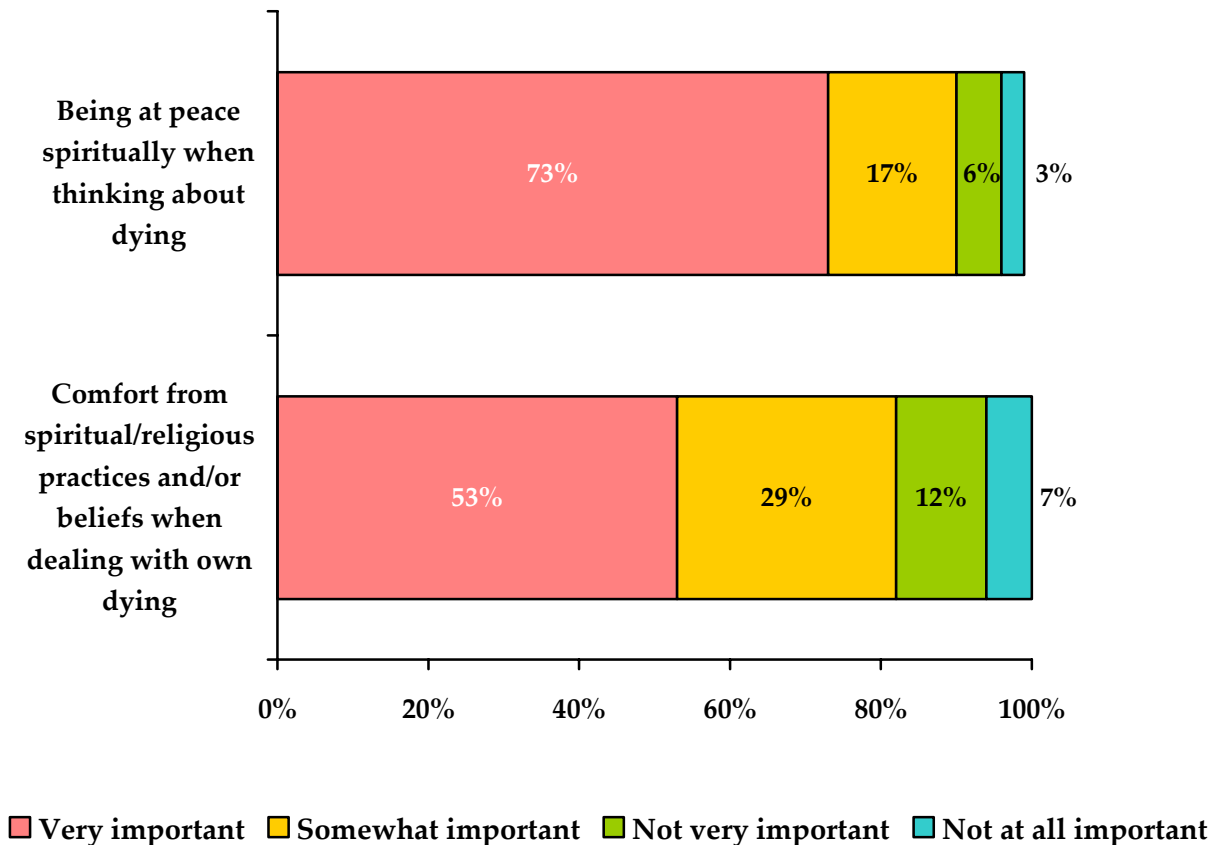
SPIRITUALITY/RELIGIOSITY

Six out of ten respondents (60%) indicate that they are affiliated with an organized faith community. Corresponding to this, slightly more than half (53%) of respondents say that comfort from religious/spiritual practices and/or beliefs would be very important to them when dealing with their own dying. Eighty-two percent indicate it would be at least somewhat important to them.

Almost three quarters (73%) say that when thinking about death they consider being at peace spiritually very important.

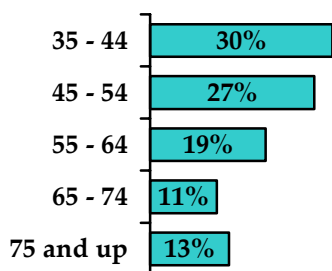
Few respondents (3%) indicate having talked with clergy regarding their wishes for care near the end of life though 19 percent want clergy to initiate a conversation regarding end-of-life issues and 22 percent indicate they would trust clergy to provide information on end-of-life issues.

IMPORTANCE OF SPIRITUAL/RELIGIOUS PEACE AND COMFORT
N = 755



RESPONDENT PROFILE

- Forty-seven percent of respondents are male; 53 percent are female.
- Two percent of respondents are Hispanic or Latino.
- Ninety-three percent of respondents are white, 3 percent are black or African American, 2 percent are American Indian or Alaskan Native, 1 percent are Asian and the remaining 2 percent list ‘other.’
- Ninety-nine percent list English as their preferred language for reading and discussing information related to death and dying.
- In terms of age, the respondent profile breaks down as follows:



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- Fifty-four percent of respondents are married, 16 percent are divorced, 14 percent are single or never married, 11 percent are widowed, 3 percent are living with a partner, and 2 percent are separated.
 - Nearly one-third of respondents have some college or technical training beyond high school (32%) while 23 percent have a high school diploma or equivalent; 19 percent are college graduates and 22 percent have a post-graduate or professional degree.
 - The majority of the sample are employed full-time (54%) and 24 percent are retired or not working.
 - One in three of the sample report an annual household income of \$75,000 or more (31%), and 41 percent make between \$30,000 and \$75,000. Twenty-nine percent have a household income below \$30,000.
 - Six out of ten (60%) report being affiliated with an organized faith community.
 - Three out of ten (30%) respondents are AARP members.
 - Nearly one in four respondents rates their health as ‘excellent’ (24%); 30 percent are in ‘very good’ health and 31 percent report their health as ‘good’. Seventeen percent report having a serious chronic illness.

- Ninety-six percent of respondents are covered by health care insurance. Four in ten (40%) report spending less than \$50 per month out-of-pocket for insurance or doctor visits and 33 percent report spending between \$50 and less than \$200 per month. Eighteen percent report spending between \$200 and less than \$500 per month on insurance or doctor visits. Almost six out of ten (58%) respondents report spending less than \$50 per month on prescription drugs, while 34 percent spend between \$50 and \$200 out of their own pockets on prescription drugs.

CONCLUSIONS

GAPS BETWEEN THOUGHTS AND ACTIONS:

An analysis of the data reveals several important gaps between what a majority of respondents think about issues related to death and dying and what corresponding actions they take. Though the majority of respondents report being comfortable talking about death (86% report being at least somewhat comfortable) only a small majority have had conversations regarding their wishes for care near the end of life with their family members (57%) or their spouse/partner (53%). Only 8 percent of respondents report having talked about their end-of-life care wishes with their primary care physician though 43 percent say they would want their primary care physician to initiate a conversation with them regarding end-of-life issues. Notably, the gap between the percentage of respondents who report having spoken with a lawyer regarding their end-of-life care wishes (17%) and those who would want a lawyer to initiate a conversation with them regarding end-of-life issues (21%) is far smaller than those who have talked with their primary care physician (8%) and those who want their primary care physician to initiate the discussion (43%).

When considering dealing with their own dying, a full 72 percent of respondents indicate that being able to complete a Last Will and Testament is very important (96 percent think it is at least somewhat important) and 85 percent report being at least somewhat comfortable writing their own will, yet only 46 percent of respondents have actually completed one. Similarly, majorities of respondents consider certain health conditions as worse than death¹ and 71 percent report that when thinking about dying they consider being off machines that extend life, such as life support, very important. Yet, only 26 percent have completed a living will or other written instructions stating the kind of health care they do or do not want under certain circumstances. When considering their own dying, 66 percent say it would be very important to be able to stay in their own home and a full 94 percent indicate that being able to stay at home would be at least somewhat important to them. Correspondingly, 69 percent are at least somewhat afraid of dying in an institution such as a nursing home or hospital. Yet, only 37 percent have completed designating a health care proxy or durable power of attorney for health care who could help ensure their choices (such as staying at home) were followed should they become incapacitated. While only 37 percent have designated a health care proxy, 63 percent report being very comfortable doing so.

PROVIDER EXPECTATIONS:

Another important theme emerging from this survey is the variety of expectations respondents have for their health care providers. Ninety-three percent of survey respondents report that honest answers from their doctor would be very important to them when dealing with their own dying, but fewer respondents report they strongly agree that they would want to know if they had a serious illness (76%) or if they only had a few months to live (77%). When considering dealing with their own dying, 71 percent of respondents say it would be very important to them to have good relationships with their health care providers and 87 percent say it would be very important for them to understand their treatment options, yet less

¹ 64% of respondents indicate they think that living with great pain is worse than death; 86% think total physical dependency on others, such as being in a coma is worse than death; 75% say not being able to communicate their wishes and/or needs with family and friends is worse than death; and 76% say severe mental deterioration or severe memory loss are worse than death. 8% say nothing is worse than death.

than half of respondents say they would trust a primary care physician (48%) or medical specialists, such as: cardiologists, oncologists (29%) to provide information on end-of-life issues. Forty-six percent of respondents have at least some fear that their doctor may not believe they are in pain or may not treat their pain and over one third of respondents (34%) have at least some fear that they would be given too much pain medicine.

The majority of respondents expect to need a variety of types of support when they are near the end of life, and some respondents expect this support to be provided by health care providers. Fifty-two percent of respondents expect that near the end of life they will want health providers to listen when they talk and 55 percent expect health providers to know about their illness. One-third of respondents (33%) expect health providers to encourage them when they are down. Notably, only 29 percent of respondents think health providers should know what they (respondents) want when they die.

SUPPORT EXPECTATIONS:

The vast majority of respondents expect to need multiple types of support near the end of life. The survey listed eight types of support from which respondents could chose all those they expect to need. Ninety-seven percent expect to need others to listen when they talk; 94 percent expect they will need transportation provided; 95 percent expect help with chores; 89 percent expect they will need others to do fun things with them; 96 percent expect they will want others to know what they want when they die; 84 percent expect help caring for other family members; 92 percent expect encouragement when they are down; and 96 percent expect others to know about their illness. Sizeable majorities of respondents chose each of these types of support, perhaps reflecting a realistic recognition of the complex support needs that often accompany modern dying.

EFFECTS ON FAMILY:

For each type of support respondents expect to need, they were asked to select all those who they thought should provide that support. Though, 83 percent report that when thinking about dying they consider not being a physical burden on loved ones very important, in every one of the eight categories of support, children and other family were selected to be the ones to provide that support by the largest majorities of respondents. Spouse/partners were chosen by the second largest majority every time. Correspondingly, when considering their own dying, 80 percent of respondents think it would be very important to have their family and friends visiting them and 72 percent say that it would be at least somewhat important to review their life history with their family. These data suggest that respondents have expectations for family to provide multiple types of support near the end of life. Yet, while maintaining high expectations for support from family near the end of their lives, respondents on the whole were ambivalent about whether caring for people who are dying is a rewarding experience. Only 38 percent strongly agreed with this statement, and almost a quarter of respondents (23%) registered some disagreement with it.

Some respondents have concerns about how death and dying will effect their family's financial situation. Thirty-four percent report being very concerned that their family's money will not last and 36 percent are very concerned they will be a financial burden to their family or friends. Thirty-five percent are very concerned their own (or their spouse/partner's) money will not last.

CONCERNING PAIN:

Eighty-seven percent of respondents are at least somewhat afraid of dying painfully. And 80 percent say it would be very important to them to know good pain management was available to them when they consider dealing with their own dying. Yet, many also have some fears about pain management. Forty-six percent are at least somewhat afraid that their doctor may not believe they are in pain or may not treat their pain, while 34 percent of respondents report being at least somewhat afraid they will be given too much pain medicine. More than one-third (35%) are at least somewhat afraid that they will become addicted to pain medicines over time. In addition to the fears that more than one-third of respondents have regarding pain management near the end of life, a majority of respondents also have concerns about pain management practice. Eighty percent of respondents at least somewhat agree that they would only take pain medicines when the pain is severe and 73 percent of respondents at least somewhat agree that they would take the lowest amount of pain medicine possible to save larger doses for later when the pain is worse. The majority of pain management experts agree that this is not the most effective way to manage pain.

CONCERNING HOSPICE:

While only 6 percent of respondents report never having heard about hospice services, 39 percent report having only heard a little about hospice services. Fifty-five percent say they have heard a lot about hospice services. Yet, 45 percent of respondents were not aware that Medicare and Medicaid pay for hospice services, and 21 percent were unsure. Furthermore, 17 percent of respondents who had heard about hospice services were not sure whether they would consider using them. The majority of those who had heard of hospice services would want to receive hospice support in their own home (89%). Small minorities indicate they would want to receive hospice support in a nursing home (12%), in a hospital (19%), in a residential facility such as assisted living (23%) or in a hospice residence (32%). These data suggest that education about hospice services, reimbursement options, and the benefits of receiving hospice support in any care environment that one might find oneself near the end of life may be indicated.

METHODOLOGY

In March and April 2005, The Massachusetts Commission on End of Life Care conducted a random sample mailed survey of Massachusetts residents age 35 and older, who had telephone service. The sample was purchased from Accudata American, the largest independent list broker in the nation. Accudata lists are compiled from a variety of sources including telephone directories, public records, U.S. Census Bureau, U.S. Postal Service information, surveys, birth records, door-to-door canvassing, warranty cards, mortgage data and more. The specifications were for a sample containing half male and half female and additional demographic information: area code, length of residence, education, ethnicity, income, marital status, and county. To select the Random Nth and obtain a True Sampling, the computer randomly chose across the entire list to provide an even distribution of the selected demographics.

The 3,000 residents in the sample received three pieces of mail: a pre-notification postcard, the survey along with a cover letter that explained the purpose of the survey (see Appendix 2), and a reminder postcard, if they had not returned the survey within three weeks. Those who had not returned a survey were called and offered another survey. A total of 778 completed surveys were returned by the cutoff date four weeks later. A participation incentive was offered. Everyone who returned a survey was eligible for one of five \$100 awards. The respondents were directed to mail a postcard with their name and address separate from the survey, thus they did not put their name and address on the survey.

A weighting schedule for each gender/age group was prepared to match the United States Census for Massachusetts to make it generalizable to the overall population. This weighting process required the elimination of twenty-one surveys. Two surveys were completed by persons under 35 years of age. A total of 755 respondents remained in the sample. This yielded a twenty-five percent rate of return. Weights ranging from .56 to 3.56 were applied to the survey results to reflect the distribution of age and gender of residents in Massachusetts.

The survey has a sampling error of plus or minus 3.5 percent. This means that out of 100 samples of this size, the results obtained in the sample would fall in a range of plus or minus 3.5 percentage points of what would have been obtained if every Massachusetts resident age 35 and older had been surveyed. All percentages in the report and annotated survey are based on the weighted data.

The database was written using SPSS Data Entry Builder and the data analyzed using SPSS statistical software. After applying weights to the data, frequencies were run on all variables of interest. Also, tests of significance were conducted, when appropriate, to examine differences between various groups of interest.

The percentages presented for each question in this report are the "valid percentages," meaning they were computed using the valid sample size for each question. To compute the valid sample size for each question, respondents with missing or non-responsive answers were subtracted from the total number of respondents. The valid percentages for a given question should add to approximately 100% (slightly more or less than 100% because of rounding

error). The percentages for the missing / non-responsive answers are separate from the valid percentages and are not included in this sum.

A Respondent/Non-Respondent Analysis was conducted from the initial random sample database for the two groups to insure that there were no demographic differences between those who chose to respond to the survey and those that did not. A chi-square analysis using area code, length of residence, education, ethnicity, income, marital status, and county was completed. No significant differences that would affect the results were found.

SURVEY HISTORY

The survey is adapted from the original Life's End Institute: *Missoula Demonstration Project's* Community Survey. In 1997, Life's End Institute completed a seventy-three item comprehensive survey in Missoula County, Montana to determine prevailing attitudes, expectations and experiences with the dying process. Two comparison communities were also surveyed: Bannock County, Idaho and Albany County, Wyoming.

Using modified questions and a modified response scale from the Corriveau-Kelly Death Anxiety Scale (which itself was built upon Templer's Death Anxiety Scale), the survey tool gathers basic demographic information as well as data related to advance care planning, knowledge of hospice services, spiritual beliefs and customs related to death and dying, preferred medical practices, financial concerns, pain management and social support systems.

The data from the survey have proven to be useful, serving as the basis for several community engagement initiatives in Missoula County. Since its inception, the Missoula Community Survey has been adapted for statewide use and has been successfully used in several communities and states nationwide.

**APPENDIX 1
ADVISORY COMMITTEE**

The Massachusetts Commission on End of Life Care received valuable input regarding the statewide survey project from the following distinguished Advisory Committee:

Name	Title	Organization
Pam Albert	Director of Donor Family Services	New England Organ Bank
David Ball	Vice President	Massachusetts Extended Care Federation
Deborah Banda	State Director	AARP Massachusetts
Michael Banville	Director of Quality Improvement	Mass-ALFA
Richard Beaman	Project Director	Center for Health Policy and Research, UMass Medical School
Harris Berman, MD	Dean, Public Health & Professional Degree Programs	Tufts University School of Medicine
Cynthia Boddie-Willis, MD	Director, Division of Health Promotion and Disease Prevention	Massachusetts Department of Public Health
Mary Lou Buyse, MD	President	MA Association of Health Plans
Andrea Cohen	CEO	Houseworks
Rigney Cunningham	Executive Director	Hospice & Palliative Care Federation of Massachusetts
Marcie Freeman	Director, Outreach and Recruitment and Chair, Multicultural Coalition on Aging	Hebrew Senior Life, Research & Training Institute
Amy Goldstein	MA Pain Initiative Coordinator	American Cancer Society
Ronald Hollander	President	Massachusetts Hospital Association
David Kaufman, MD	Chief, Critical Care Medicine	St. Vincent Hospital
Leslie Kirle	Senior Director for Clinical Policy and Patient Advocacy	Massachusetts Hospital Association
Ellen Leiter	Executive Director	HealthCare Dimensions
Arlene Lowney	Executive Director	MA Compassionate Care Coalition
Jean Marchant, M.Div.	Director, Office of Health Care Ministry	Roman Catholic Archdiocese of Boston
Christine McCluskey	Executive Director	Central MA Partnership to Improve Care at the End of Life
Clare D. McGorrian	Attorney	
Pamela Meister	Assistant Attorney General	Office of the Attorney General
Dolores E. Mitchell	Executive Director	Group Insurance Commission
Abraham Morse	President	Massachusetts Extended Care

Name	Title	Organization
		Federation
Anita Nasra	Assistant Director	Kit Clark Senior Services
Rev. Dr. Gordon Postill	Spiritual Counselor	Old Colony Hospice
Lucilia Prates	Director	MA Medicare & Medicaid Outreach & Education Program
Barbra Rabson	Executive Director	MA Health Quality Partners
Betty Anne Ritcey	Director of Service Planning and Coordination	Executive Office of Health and Human Services
Julie Rosen	Executive Director	The Kenneth B. Schwartz Center
Palmira Santos	Director, Comprehensive Cancer Control and Prevention Program	Massachusetts Department of Public Health
Craig Schneider	Manager, Medicare Financial Management Branch	Centers for Medicare & Medicaid Services
Robert Schreiber, MD	Physician-in-Chief	Hebrew Senior Life
Brunilda Torres	Director, Office of Multicultural Health	Department of Public Health
Nancy Turnbull	Executive Director	Massachusetts Medicaid Policy Institute
Carol Wogrin	Director	Mt. Ida Center for Death Education
Charlotte Yeh, MD	Regional Administrator	Centers for Medicare & Medicaid Services
Zi Zhang	Director, Health Survey Program	Department of Public Health