

# MA Commission on End of Life Care Survey Project Executive Summary

## Background

The Massachusetts Commission on End of Life Care, AARP Massachusetts and Life's End Institute: *The Missoula Demonstration Project* have collaborated on a first-ever effort to gather Massachusetts-specific data about concerns and attitudes toward end-of-life issues. The questions focused on:

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

Two surveys (with the same survey questions) were distributed during March and April of 2005.<sup>1</sup> Working on behalf of the Massachusetts Commission on End of Life Care, Life's End Institute: *The Missoula Demonstration Project* sent one survey to a random sample of 3,000 Massachusetts residents age 35 and over. AARP sent one survey to a random sample of 3,000 AARP members in Massachusetts age 50 and older. The general population random sample yielded a response from 755 people (a 25% response rate). The AARP random Massachusetts member sample yielded 1,448 responses (a 48% response rate).

## Key Findings

**Overview: Concern about quality of life at the end of life emerged as a consistent theme as people expressed their desire for**

- **communication**
- **connections**
- **comfort**
- **control**

### ***Communication***

**People are willing to talk about death but conversations about wishes for care near the end of life generally do not take place with anyone other than family. There is a gap between the percentage of respondents who have spoken with a physician about their wishes for care near the end of life and those who would like their primary care physician to initiate such a conversation.**

- People indicate a willingness to talk about death. More than 8 out of 10 respondents from each of the survey sample populations report that they are very or somewhat comfortable talking about death. Only 2% of the respondents to each of the surveys

---

<sup>1</sup> A distinguished Advisory Committee consisting of 37 people (see attached list) with expertise in aging services, medicine, hospice, home health care, long term care, hospitals, employer health plans, research and data analysis, pastoral care, ethnic and linguistic minority issues, education, managed care, pain management, and public health assisted in adapting the survey questions for use in Massachusetts and in interpreting the survey findings.

indicate that they are not at all comfortable talking about death. Death is not necessarily a taboo subject anymore.

- When respondents were asked who they had talked with about their wishes for care near the end of life, the most frequent answers were family and spouse/partner. Sixty-five percent of the AARP member respondents and 37% of the general population respondents have spoken to a spouse/partner and/or other family member about their wishes for care near the end of life but have not spoken to anyone else. Ten percent of the AARP member respondents and 17% of the general population respondents have not spoken to anyone about their wishes for care near the end of life. When asked who they would want to initiate a conversation about end-of-life issues, only 4% of the general population respondents and 5% of the AARP member respondents said “no one.”
- There is a gap between the percentage of respondents who have spoken with a physician about their wishes for care near the end of life and those who would like their primary care physician to initiate a conversation about end-of-life issues. Less than 1 in 10 of the general population respondents and less than 2 in 10 of the AARP member respondents have talked with their primary care physician about their wishes for care near the end of life. More than 4 in 10 respondents from each of the survey sample populations indicate that they would like a primary care physician to initiate a conversation about end-of-life issues and more than 2 in 10 would like a medical specialist such as a cardiologist or oncologist to initiate the conversation.
- Just over half of the AARP member respondents and just under half of the general population respondents indicate that they would trust a primary care physician to provide information on end-of-life issues. More than 2 in 10 respondents from each of the survey sample populations would trust a medical specialist to provide information on end-of-life issues.

**Communication and relationships with doctors are very important to respondents from each survey sample population.**

- Honest answers from doctors and understanding treatment options were considered very important by the greatest number of respondents when asked about the importance of various factors when dealing with their own dying. At least 89% of the respondents to each of the surveys indicate that honest answers from their doctor would be VERY important to them when dealing with their own dying while 87% indicate that understanding their treatment options would be VERY important.
- There may be some ambivalence however, as fewer (although still more than 7 out of 10) respondents from each survey sample strongly agree that they would want to know if they had a serious illness. More than 9 out of 10 at least somewhat agree that they would want to know if they had a serious illness. Similarly, more than 7 out of 10 respondents from each survey sample strongly agree that they would want to know if they only had a few months to live and almost 9 in 10 at least somewhat agree.
- Having good relationships with health care providers is considered to be very important by at least 7 in 10 respondents from each of the survey sample populations.

**Connections**

**Both surveys reveal that people need and expect family connections and support at the end of life but don't want to be a burden on their families.**

- More than 8 out of 10 respondents to each of the surveys indicate that not being a physical burden to loved ones is VERY important when they think about dying and more than 95% say it is at least somewhat important not to be a physical burden. More than 60% of the respondents to each survey are very or somewhat concerned that they will be a financial burden to family or friends.
- However, at least 2/3 of the respondents to each of the surveys expect to need each of the types of support listed in the survey – listen when I talk, know what I want when I die, know about my illness, help with chores, provide transportation, encourage me when I'm down, do fun things with me, and help care for other family members. In each of the 8 categories, children and other family members were selected as the ones expected to provide the support by the largest numbers of respondents. Spouse/partners were chosen by the second largest majorities each time.
- Connections with family and friends are also considered important. More than 7 in 10 respondents to each of the surveys indicate that visits from family/friends would be VERY important when dealing with their own dying. Having relationships settled with the family is VERY important to more than 7 in 10 respondents to each of the surveys when they think about dying.

## **Comfort**

**People share similar fears about death and dying. Dying painfully is the top fear. But there are also fears about addiction to pain medications and other side effects.**

- More than 8 in 10 respondents from each of the survey sample populations are afraid of dying painfully. More than 4 in 10 fear that their doctor may not believe they are in pain or may not treat their pain. More than 6 in 10 of the respondents to each of the surveys indicate that they consider living with great pain to be worse than death. More than 7 in 10 respondents to each of the surveys indicate that being free from pain is very important when they think about dying.
- At least 8 in 10 respondents from each of the survey sample populations indicate that knowing that medicine would be available and having good pain management available would be very important to them when dealing with their own dying.
- Yet both surveys show that at least 3 in 10 respondents to each of the surveys fear getting too much medicine and more than 3 in 10 fear addiction to pain medication over time. More than 7 in 10 would take the lowest possible amount of pain medication and save larger doses for when pain becomes more severe. *(Experts generally agree that this approach is not the most effective use of pain medication and does not produce the greatest reduction of pain.)*

**Desired comfort includes psychological, spiritual and emotional components.**

- More than 2/3 of the respondents to each of the surveys indicate that comfort from religious/spiritual practices and/or beliefs would be very or somewhat important to them when dealing with their own dying.
- However, less than one-quarter of the respondents from each of the survey sample populations would trust clergy to provide information about end-of-life issues. Less than 5% of respondents from each of the survey sample populations have spoken to clergy about their end of life wishes. But only 19% of the general population respondents and 17% of the AARP member respondents would want clergy to initiate a conversation with them regarding end-of-life issues.

- More than 2/3 of the respondents to each of the surveys indicate that being at peace spiritually is very important to them when they think about dying and more than 85% indicate that it is very or somewhat important.
- At least 57% of the respondents to each of the surveys indicate that having a sense of their own self-worth is very important to them when they think about dying and at least 84% indicate that having a sense of their own self-worth is very or somewhat important.
- However, only 16% of the general population respondents and 13% of the AARP member respondents would trust mental health professionals to provide information on end of life issues. Only 3% of the respondents from each of the survey sample populations have spoken with a mental health professional such as a social worker, psychologist or psychiatrist about their end of life wishes.

## ***Control***

**Both surveys reveal a gap between the personal preferences people express about death and dying and the actions they take to have those preferences known and honored.**

- Over 85% of the respondents from each of the survey sample populations indicate that total physical dependency on others, such as being in a coma is worse than death. Over 3/4 indicate that severe mental deterioration or severe memory loss is worse than death. Three-quarters say they think not being able to communicate their wishes or needs to family or friends is worse than death. Less than 1 in 10 said that nothing is worse than death.
- More than 75% of respondents to each of the surveys indicate that being able to balance alertness and pain management is very important when they think about dying and at least 95% indicate it is at least somewhat important. Seven in 10 respondents to each of the surveys say it is very important to be off machines that extend life when they think about dying and over 89% say it is at least somewhat important.
- Yet only 37% of the general population respondents and 59% of the AARP member respondents have appointed a health care proxy to act for them if they are unable to speak.

## ***Hospice***

**All but a few of the respondents in each of the survey sample populations have heard of hospice.**

- Of the more than 90% who have heard at least something about hospice, more than 3/4 would consider using hospice services. More than 2/3 of the people who knew about hospice services learned about it from someone who had used hospice.
- Fifty-five percent have heard a lot about hospice but less than 40% know that Medicare and Medicaid pay for hospice services.
- One question on the surveys includes a list of possible places to receive hospice support and asks respondents to check all of the places that they would want to

receive such support. More than 80% of the respondents to each of the surveys checked their own homes. At least 3 in 10 checked a hospice residence.

### **Observation:**

What people say they want at the end of life (the quality of life that results from good communication, connections, comfort, and control) is available. It may not be the norm throughout the Commonwealth but it is the core of hospice, palliative care, and other supportive community programs. To the extent that death is no longer a taboo subject, improved communication and dialogue, particularly between the patient, his/her family and the physician can start to bring us closer to delivering what people say they want.

### **Challenge Statements:**

The data suggest a number of opportunities – call them challenges – for those providing care near the end of life:

- Challenge doctors to explain treatment options at the end of life, including hospice.
- Challenge medical boards and other medical and health care-related professional societies to establish norms making conversations about end of life issues a routine part of clinical practice at various points in the life cycle.
- Challenge health care institutions across the spectrum of clinical environments to focus on making improved pain management a priority.
- Challenge health care institutions and researchers to devote more attention to understanding the end of life perspectives, concerns and needs of diverse populations.
- Challenge family caregivers, clergy, lawyers and financial planners to promote conversations about end of life decision-making and encourage family members to appoint health care proxies.
- Challenge hospice programs to deepen public understanding about hospice while continuing their efforts to cultivate collaborations with doctors and other referral sources.
- Challenge hospice and payers to explore options to make residential hospice accessible, including reimbursement for room and board.

**The Massachusetts Commission on End of Life Care would like to thank the following organizations for their support of this survey project:**

- **AARP Massachusetts**
- **Dana-Farber Cancer Institute and HealthCare Dimensions Hospice**
- **The Commonwealth's Group Insurance Commission & its Indemnity Plan administered by Unicare**
- **Hebrew Senior Life**
- **The Massachusetts Medical Society**
- **Partners Health Care**
- **Rallying Points (The Robert Wood Johnson Foundation)**
- **Wellpoint, Inc. (Unicare)**

## 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 Kirlle	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 Federation

<b>Name</b>	<b>Title</b>	<b>Organization</b>
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	Massachusetts 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	Massachusetts Department of Public Health

# MA Commission on End of Life Care Survey Project

## Key Findings

### Overview:

**Concern about quality of life at the end of life emerged as a consistent theme as people expressed their desire for**

- **communication**
- **connections**
- **comfort**
- **control**

**Observation: What people describe wanting is the core of hospice, palliative care, and some other supportive community programs.**

### Key Findings:

1. People are willing to talk about death. Death is not necessarily a taboo subject.
  - More than 8 in 10 respondents to each of the surveys indicate that they are very or somewhat comfortable talking about death. Only 2% indicate they are not at all comfortable talking about death.
  - When asked who they would want to initiate a conversation about end-of-life issues, only 4% of the general population respondents and 5% of the AARP members said “no one.”
2. Although family is central when it comes to discussing end of life preferences, people want involvement from their doctors in the form of honest answers and an understanding of their treatment options.
  - Honest answers from doctors and understanding treatment options were considered **VERY IMPORTANT** by the greatest number of respondents (more than 85% from each survey) when asked how important various things would be when dealing with their own dying.
  - More than 4 in 10 respondents from each of the survey sample populations indicate that they would like a primary care physician to initiate a conversation about end-of-life issues.
3. Both surveys reveal a gap between the personal preferences people express about death and dying and the actions they take to have those preferences known and honored.

- Seven in 10 respondents to each of the surveys say it is very important to be off machines that extend life when they think about dying and over 89% say it is at least somewhat important. Yet only 37% of the general population respondents and 59% of the AARP member respondents have appointed a health care proxy to act for them if they are unable to speak.
4. People want medicine and good pain management to be available.
- At least 8 in 10 respondents from each of the survey sample populations indicate that knowing that medicine would be available and having good pain management available would be very important to them when dealing with their own dying.
  - More than 8 in 10 respondents from each of the survey sample populations are very or somewhat afraid of dying painfully.
  - More than 7 in 10 respondents to each of the surveys indicate that being free from pain is very important when they think about dying. More than 2/3 of the respondents to each of the surveys indicate that they consider living with great pain to be worse than death.
  - More than 4 in 10 fear that their doctor may not believe they are in pain or may not treat their pain.
5. Of the more than 90% of respondents who had heard at least something about hospice, more than  $\frac{3}{4}$  would consider using hospice services.