

Massachusetts Commission on End of Life Care

Report to the Massachusetts Legislature for the period May, 2002 – June, 2003 (revised as of January 13, 2004)

Background: The mission of the Massachusetts Commission on End of Life Care (the “Commission”) is “To improve the quality of life at the end of life.” The Commission strives to accomplish its mission by focusing its efforts on:

- Public awareness, education and engagement;
- Professional and institutional awareness, education and engagement;
- Advocacy initiatives; and
- Media outreach.

Use of Web site and Resource Guide: The Commission spent most of its state-funded budget for FY '01 and FY '02 to:

1. Create a Web site (www.endoflifecommission.org) with an online searchable database of services available in communities throughout the Commonwealth; and
2. Publish and distribute a Resource Guide derived from the online database of services.

These efforts have reached a broad audience. Approximately 4,500 copies of the print version of the Resource Guide were distributed statewide to libraries, Councils on Aging, Boards of Health, community health centers, funeral homes, home care agencies, hospitals and others. Copies are now available for purchase at the State House Bookstore.

The Commission’s Web site recorded more than 63,000 user sessions during the first six months of 2003. Use continues to average over 10,500 sessions a month. The Web site provides a cost-effective way to educate and link individuals with life-threatening illnesses, their families, caregivers and health care professionals with the end of life resources and services that currently exist in their local communities.

Other FY’03 efforts: The Commission started FY '03 with the following priorities:

1. Keep the online resource guide current by updating the services listed and expanding consumer information and resources.
2. Improve public education and awareness about end of life issues and, in particular, to promote dialogue about the sorts of decisions and choices that individuals and families face as family members age and medical technology evolves.
3. Compile and assess available data about the needs and gaps that exist in end of life services in Massachusetts.
4. Convene interested parties with a role to play in improving end of life care to assist in the development of public policy recommendations.

Due to lack of funding, the Commission had to scale back its efforts during FY '03. The Commission is extremely grateful for the legislative support it received throughout the FY '03 state budget process. Unfortunately, due to the state budget crisis, funding for the Commission was not included in the final budget. However, the Commission continued to meet during FY '03 and operated with volunteer labor and in-kind support from Commission members and their agencies or organizations.

The Commission promoted public education and awareness by working with the Hospice and Palliative Care Federation of Massachusetts, the Massachusetts Compassionate Care Coalition and the Massachusetts Medical Society to prepare press releases and contact reporters about the sobering news contained in *Means to a Better End: A Report on Dying in America Today* ("MTBE"). Funded by The Robert Wood Johnson Foundation, MTBE rated each of the 50 states and the District of Columbia on eight criteria as a basis for assessing the state of end-of-life care in America. The report, released on November 18, 2002, highlighted the problems that Americans have in finding good care for their loved ones or for themselves when facing life-threatening illness and indicated that the situation is no better in Massachusetts. Excellent end-of-life care is available in Massachusetts but, as in most other states, excellent end-of-life care is not the norm. The Commission was gratified by the resulting news stories at the time MTBE was released and by the Boston Globe editorial on December 28, 2002 (copy attached).

Further, the Commission used *Means to a Better End* as the basis for a series of key informant interviews with end-of-life experts in Massachusetts. The goal was to gather additional information in order to better evaluate the scores Massachusetts received on the eight indicators measured in MTBE and possible public policy responses. The Commission will use that information when selecting FY '04 priorities.

Members of the Commission also promoted public education and awareness by integrating end-of-life issues into their ongoing programs and services and seeking opportunities to speak and hold workshops at professional conferences. The efforts of Commission members resulted in workshops on end-of-life care at major statewide conferences such as the annual meeting of the Massachusetts Councils on Aging, the Western Massachusetts Elder Care Conference, and the statewide Cancer Control Conference. In addition, ombudsmen and staff from the Massachusetts Caregivers program operated by the Executive Office of Elder Affairs received training about end-of-life issues and the use of the Commission's Resource Guide and Web site. The Commission worked with the Tufts Health Care Institute on its end-of-life training program for case managers employed by health maintenance organizations in Massachusetts.

Finally, members of the Commission collaborated with other organizations addressing end-of-life issues in Massachusetts. For example, members of the Commission worked with the Massachusetts Pain Initiative to develop their policy agenda to promote better pain management in Massachusetts. The Commission co-sponsored a Massachusetts Hospital Association educational program called *Essential Elements of Quality Palliative Care* along with the Hospice and Palliative Care Federation of Massachusetts, and The Kenneth B. Schwartz Center. The Commission's Executive Director attended a "listening conference" sponsored by the National Association of Attorneys General on the role of Attorneys General in improving end-of-life care

and the Commission then began an ongoing collaboration with the Office of Massachusetts Attorney General Thomas Reilly. The Commission also benefited from the public outreach conducted by Craven & Ober, Policy Strategists, LLC through a public education spot on “Beacon Hill Update” (Radio station WBSM – 1420 AM) that featured the activities and efforts of the Commission and promoted its Web site, www.endoflifecommission.org.

Prospects for FY '04: Lack of public funding for FY '03 coupled with the absence of any vehicle to enable the Commission to raise private funds, slowed the Commission's efforts in FY '03. Due to continued budget constraints, legislation to create a retained revenue account for the Commission was introduced by Senator Richard T. Moore and Representative Eugene O'Flaherty and was enacted for FY '04. This account allows the Commission to raise funds from private sources and disburse them to operate the Commission and fund projects related to end-of-life care.

In the coming year, the Commission plans to seek opportunities for further collaboration with interested parties around the state with a role to play in improving the quality of life at the end of life. These activities will assist the Commission in its efforts to develop public policy recommendations. Further, the Commission will focus on fund-raising efforts in order to pursue projects to promote awareness, education and engagement as well as improved public policy. Depending on the success of its fundraising initiatives, these efforts are likely to focus on:

- Updating the content of the Commission's Web site and Resource Guide;
- Promoting advance care planning;
- Improving and publicizing the Massachusetts Comfort Care program for out-of-hospital Do Not Resuscitate Order;
- Working with the Massachusetts Pain Initiative to promote improved pain policy;
- Participating with the Massachusetts Compassionate Care Coalition's effort to promote better care at the end of life through education and engagement of clergy; and
- Attempting to assure that efforts to improve end-of-life care recognize that Massachusetts is multi-cultural and address the needs of diverse populations.

Finally, the Commission is extremely grateful that the Massachusetts Medical Society, one of the organizations authorized to have a representative serve on the Commission, has generously agreed to assume the cost and operation of the Commission's Web site for FY '04.

A BOSTON GLOBE EDITORIAL

Last Rights

12/28/2002

MORE THAN 70 percent of Americans say they would prefer to die at home rather than in a hospital or institution. But only 25 percent get their wish; 22 percent in Massachusetts. This is just one way in which Americans' way of dying is at odds with their wishes. In an effort to move those wishes to the forefront, a national coalition called Last Acts published a report last month that grades the states on several indicators of how well they facilitate the decisions that lead to deaths in the company of loved ones with as little pain as possible.

Massachusetts scored poorly on several indicators, including its below-average percentage of patients dying at home. To the state's credit, dying patients here were somewhat less likely than elsewhere to spend extended periods of time in intensive care units. As the state's own Commission on End of Life Care notes, excellent care for the terminally ill is available in Massachusetts, but it is not the norm, either here or in most other states.

There are several reasons for this, chief among them the reluctance of patients, doctors, and family members to talk about death, even when it is imminent.

One of the strongest recommendations contained in the Last Acts report is that health care leaders "work with clinicians on key communications skills: breaking bad news and setting realistic treatment goals. Currently, few know how to do this well."

One subject for physicians to discuss with patients and family members, for example, is whether to begin a feeding tube. Once it is in place, a decision to stop it is difficult.

The main reason that health care providers should encourage palliative care options for patients and their families is that every poll indicates the appeal of these alternatives. But it is also true that, compared with traditional care for the terminally ill, the use of hospices and living wills or other "advance directives" saves money. According to Last Acts, the savings can be as great as 25 to 40 percent in the last month of life. With health costs skyrocketing and shouldering aside other social needs, it makes public policy sense to support palliative options.

There is much discussion in the Last Acts report about improving state laws on pain management and increasing the numbers of physicians and nurses who have been certified in palliative care or at least received training in this field. But as Margaret Metzger, executive director of the Massachusetts Commission on End of Life Care, says, the great need is to change the expectations of patients and their families and the cultural factors in medicine that encourage intrusive, often uncomfortable treatments up to the very end. Denial of death as a social norm means denying patients the kind of death most say they want.

This story ran on page A18 of the Boston Globe on 12/28/2002.

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