

Massachusetts Commission on End of Life Care

Report to the Massachusetts Legislature for the period March, 2001 – May, 2002

The Massachusetts Commission on End of Life Care was established by the Massachusetts legislature pursuant to Chapter 159, Section 480 of the Acts of 2000. Section 480 states that the Commission was formed "to study the provision of end of life care services" and was charged with preparation of "a report detailing current end of life services and recommending improvements and expansions to said services." Under Section 480, the Commission is permitted "to make policy recommendations to agencies and officers of the state and local subdivisions of government to improve end of life care" as well as "to hold regular public meetings, fact-finding hearings and other public forums."

Commission members were appointed in early 2001 and the Commission first met on March 28, 2001. The Commission has held 8 meetings since March 2001 as well as monthly Executive Committee meetings. The Commission's mission is "to improve the quality of life at the end of life".

The Commission's study of the provision of end of life care services has culminated in the creation of a resource guide that became available online on April 9, 2002 at www.endoflifecommission.org. The resource guide was developed based on a comprehensive survey mailed to over 600 agencies and organizations around the state. It was published online first in order to allow for public feedback and additional input before being printed. The print version will be published in June 2002. In addition to information about available services, the resource guide includes consumer information, checklists and answers to questions that are frequently asked by individuals and families facing life-threatening conditions.

The online resource guide provides a cost-effective way to educate and link individuals, their families, caregivers and health care professionals with the end of life resources and services that currently exist in their local communities. It enables people of all ages with life-threatening conditions and their families to access information. Further, it promotes better planning for end of life care and encourages conversations about end of life decision-making. The online resource guide can also serve as an important referral tool for health care professionals and others who field questions regarding these matters.

Individuals can search the site by region of the state either by the type of service provider or by the name of a particular agency or organization. The types of service providers and resources include specialized medical care, hospice services, palliative care for pain relief and symptom management, support services for caregivers such as home health care, respite care and adult day care, financial planning, legal matters, advance care planning, funeral arrangements, and grief and bereavement support.

Without the benefit of an advertising budget, between April 9th and May 17th the online resource guide has been used for over 8,000 sessions and 18,000 page views. The Commission is continuing to work to publish and distribute the print version of the resource guide, to enhance the content of the online version and to promote use of both versions of the resource guide.

In addition, The Commission has promoted public education and awareness about end of life issues, through distribution of print materials to the regional libraries in Massachusetts and to the libraries operated by the Massachusetts Prevention Centers.

Acknowledgements

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Commission priorities for FY '03:

1. The Commission continue to maintain the online resource guide and allocate part of its FY '03 funding to keep the services listed in the resource guide updated and to expand consumer information and resources.
2. The Commission continue its efforts to 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.
3. The Commission continue to compile and assess available data about the needs and gaps that exist in end of life services in Massachusetts.
4. The Commission convene interested parties with a role to play in improving end of life care to assist in the development of public policy recommendations.

Conclusion: While compiling the guide has contributed to our understanding of the needs and the gaps that exist in services in Massachusetts, further work is necessary to develop a more complete picture. In the coming year the Commission plans to advance its mission by compiling and assessing data and by convening 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.