

Department of Legislative Services
Maryland General Assembly
2016 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 416 (Delegate Hill, *et al.*)
Health and Government Operations

Health Care Decisions Act - End-of-Life Decision-Making Informational Booklet

This bill requires the Department of Health and Mental Hygiene (DHMH), in consultation with the State Advisory Council on Quality Care at the End of Life, to develop an end-of-life decision making information booklet by October 1, 2017. The bill requires DHMH to distribute the booklet to health care providers who treat patients with terminal illnesses, make the booklet available to the public on DHMH's website, and annually review and update the booklet, as necessary. Finally, the bill requires a health care provider to provide the booklet to a patient who has been diagnosed with a terminal illness and who inquires about receiving aid in dying from a physician, if receiving aid in dying from a physician is an option authorized by law.

Fiscal Summary

State Effect: General fund expenditures increase for the Office of Health Care Quality (OHCQ) within DHMH to print and distribute copies of the informational booklet to health care providers who treat patients with terminal illness. Under the assumptions provided by OHCQ, first-year costs could be as high as \$171,200; however, costs are likely significantly lower, as discussed below. Out-year expenditures reflect the cost of reprinting and shipping revised copies. Developing, revising, and posting the booklet on DHMH's website can be handled with existing resources.

Local Effect: None.

Small Business Effect: Minimal.

Analysis

Bill Summary: The bill defines health care provider as a person who is licensed, certified, or otherwise authorized to provide health or medical care in the ordinary course of business or practice of a profession under the Health Occupations Article.

Required Content

The booklet must contain information on health care options available to individuals diagnosed with a terminal illness, including:

- palliative care, including pain management and terminal sedation;
- hospice care;
- the use, withholding, and withdrawal of life-sustaining treatment; and
- to the extent authorized by law, receiving aid in dying, including physician prescribed medication that the individual may self-administer to bring about the individual's death.

Current Law/Background: No provision of law requires information regarding end-of-life decision making to be produced or distributed to health care providers or the public.

End-of-life Informational Booklets and Other Sources of Information

Several states and independent organizations produce and publish, typically online, end-of-life informational materials. For example, *The Michigan Physician Guide to End-of-Life Care*, produced by the Michigan Department of Public Health, the Michigan State Medical Society, Blue Cross Blue Shield Michigan, and other entities, provides information about topics including advance care planning; palliative care; withdrawing or withholding specific treatments; and the emotions, spirituality, and task of dying. The Task Force to Improve the Care of Terminally-Ill Oregonians, convened by The Center for Ethics in Health Care, Oregon Health & Science University, produced *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*. The guidebook is a 127-page document, published online, that provides information for health care professionals and institutions as they contemplate the Oregon Death with Dignity Act's implications for practice. Without endorsing or opposing the principles embodied in the Act, the guidebook presents ethical and practical guidelines to enhance compassionate care whether or not a physician or health care system is willing to participate in providing a prescription as set forth in the Act. The guidebook was first published in February 1998 and was revised in October 2004, March 2005, September 2007, and December 2008.

Many other entities also provide state-specific or general end-of-life information online. The Hospital and Health System Association of Pennsylvania maintains an end-of-life care planning web page, that provides basic information about topics including advance directives, orders for life-sustaining treatment, and organ donation, and provides links to additional online resources. The Maryland Office of the Attorney General (OAG) maintains a website that provides extensive information about advance directives and links to other information sources, as well as versions of the Maryland advance directive form in seven languages.

Aid in Dying in Maryland

The bill requires the information booklet to include, to the extent the practice is authorized by law, information about receiving aid in dying, including physician-prescribed medication that the individual may self-administer to bring about the individual's death. The bill requires a health care provider to provide the booklet to a patient who has been diagnosed with a terminal illness if the patient inquires about receiving aid in dying from a physician, if receiving aid in dying from a physician is an option authorized by law. The practice of physician aid in dying is not currently authorized in Maryland. Senate Bill 418/House Bill 404, Richard E. Israel and Roger "Pip" Moyer End-of-Life Option Act, introduced in 2016, would change this and create a process by which an individual could request and receive "aid in dying" from the individual's attending physician. The bills exempt, from civil or criminal liability, State-licensed physicians who, in compliance with specified safeguards, dispense or prescribe a lethal dose of medication following a request made by a "qualified individual." Similar bills introduced during the 2015 legislative session received hearings in both houses, but no further action was taken.

State Advisory Council on Quality Care at the End of Life

The State Advisory Council on Quality Care at the End of Life was established by Chapter 265 of 2002. The council studies the impact of State statutes, regulations, and other aspects of public policy on the provision of care at the end of life. The council monitors trends in the provision of care to patients with fatal illnesses and participates in public and professional educational efforts concerning care at the end of life. The council also advises the General Assembly, OAG, Department of Aging, and DHMH on matters related to the provision of care at the end of life.

State Expenditures: The bill requires DHMH to develop the informational booklet regardless of whether aid in dying is authorized by law in Maryland; however, a health care provider must only provide the booklet to specified individuals on request and if receiving aid in dying from a physician is authorized by law. The bill also establishes the deadline for distribution as October 1, 2017. Therefore, it is likely that some portion of initial costs may be deferred from fiscal 2017 to 2018.

Even so, OHCQ advises that the cost to print and distribute the informational booklet by mail is \$171,200 in fiscal 2017, with a similar cost annually thereafter. Out-year expenditures under this scenario reflect the cost to print and ship updated copies of the informational booklet each year. However, the Department of Legislative Services (DLS) anticipates the cost to produce and distribute the booklet to be significantly less, as discussed further below.

OHCQ advises that approximately 40,563 licensed health care providers (specifically physicians, physician assistants, and advance practice registered nurses) in Maryland *may* treat individuals with terminal illnesses. Because it is not possible to discern based on licensing data which licensees *actually* treat individuals with terminal illnesses, the estimate provided by OHCQ assumes that the informal booklet is sent to all licensees. However, DLS advises that the population of licensees could be significantly narrowed by excluding specialties and areas of practice that would be highly unlikely to interact with terminally ill individuals (who would be eligible for aid in dying under the proposal currently being considered by the Maryland General Assembly), and instead focusing distribution on specialties and practices that would be likely to interact with these individuals. For example, plastic surgeons and obstetricians would be less likely to treat patients with a terminal illness, while oncologists or providers in hospital intensive care units would be significantly more likely to treat patients with a terminal illness. OHCQ could work with the appropriate licensing authorities to better target the distribution of the informational booklet.

OHCQ advises that it anticipates the booklet to be approximately 150 pages in length, similar to *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*. As a result, printing and shipping costs are significant. However, DLS notes that the bill only requires the production of a *booklet*, not a *guidebook*, and that the booklet is intended to provide basic information on health care options available *to individuals* diagnosed as having a terminal illness. By comparison, the *guidebook* contains detailed explanations of the Oregon Department of Human Services reporting requirements, a discussion of issues related to physician liability and negligence, and a discussion of how physicians can implement a conscientious practice with regard to death with dignity. As a result, the booklet required by the bill should not be based on the Oregon guidebook and, therefore, is likely significantly shorter and less expensive to print and distribute.

OHCQ further advises that, based on its experience with other required booklets and brochures, revisions will occur annually. DLS notes that the information required to be included in the booklet can be drafted to cover important, but general, points regarding health care options for individuals diagnosed with a terminal illness and, thus, be less likely to require annual updating. As a point of reference, even given its significant detail, the

Oregon guidebook has been updated four times in the last 18 years. While revisions might be more likely to occur in the years after the booklet is first produced, it is unlikely that revision and redistribution are required every year.

OHCQ further anticipates providing one copy to each provider, under the assumption that providers must make copies for distribution to their patients. DLS disagrees with this interpretation of the bill, particularly given OHCQ's assumption of a 150-page booklet. Instead, DLS assumes multiple copies would be distributed to health care providers for them to disseminate to their patients, as permitted.

Given the smaller number of providers who would likely receive the booklet – even though they would each receive multiple copies, the reduced costs of printing and shipping the informational booklet (due to fewer total pages, even with more copies), the decreased frequency of revision and redistribution required, and the potential to defray a portion of the costs until fiscal 2018, costs are likely significantly less than the estimate provided by OHCQ. *For illustrative purposes only*, even if all such providers received 20 copies of a six-page booklet rather than one copy of a 150-page booklet, the total number of pages to be printed would be 40% of the amount assumed by OHCQ and other costs associated with covers and shipping would decrease. Applying this percentage to the OHCQ estimate of \$171,200 could result in costs of approximately \$100,000 – which may still be too high based on the number of providers.

Additional Information

Prior Introductions: None.

Cross File: SB 873 (Senator Young) - Judicial Proceedings.

Information Source(s): Department of Health and Mental Hygiene, Office of the Attorney General, *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, *The Michigan Physician Guide to End-of-Life Care*, The Hospital and Health System Association of Pennsylvania, Department of Legislative Services

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