House Legislative Analysis Section
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END OF LIFE CARE AMENDMENTS

House Bill 5148 as introduced
Sponsor: Rep. Jason Allen

House Bill 5256 as introduced
Sponsor: Rep. Randy Richardville

House Bill 5257 as introduced
Sponsor: Rep. Paula K. Zelenko

House Bill 5259 as introduced
Sponsor: Rep. Gary Woronchak

House Bill 5263 as introduced
Sponsor: Rep. Carl M. Williams

House Bill 5264 as introduced
Sponsor: Rep. Lauren Hager

House Bill 5265 as introduced
Sponsor: Rep. Andrew Raczkowski

First Analysis (10-25-01)
Committee: Health Policy

THE APPARENT PROBLEM:

Health care professionals and the general public tend to conceive of the ultimate purpose of health care in "curative" terms. In other words, people think that doctors and nurses are supposed to diagnosis medical problems and extirpate the cause of those problems at their source. If something is broken, doctors and nurses should fix it. In recent years, the health care profession has begun to focus increasing attention on the need for medical professionals and the general public to acknowledge that there are some problems that medicine simply cannot solve. This is not primarily a function of the contemporary state of health care. Although there is good reason to believe that the art and science of medicine will progress in finding cures for individual ailments and diseases, there is equally good reason to believe that medicine will never reach the point at which it is capable of curing all ailments and diseases. In recognition of this ultimate "Achilles heel," which requires all human beings to confront their own mortality, medical professionals, as well as religious leaders and ethicists, have begun to focus increasing attention on the need to promote acceptance of "palliative" care as an essential component of high quality health care. Palliative care mitigates the symptoms or effects of a disease—pain, in particular—once health care professionals and their patients have come to terms with the difficulty or impracticability of finding a cure. In colloquial terms, if there is a problem, then doctors should fix it; however, while they are trying to fix the problem, or once they come to the realization that they cannot fix it, they should at least try to alleviate the problem's effects.

Patients who have a reduced life expectancy due to an advanced illness are frequently in need of palliative care, though the need for such care is certainly not exclusive to patients who are nearing the end of life. Because patients may not conceive of palliative care as an essential element of their health care, some people believe that health care facilities and agencies should be required to notify patients that pain and symptom management is a basic element of medical practice. Moreover, some people believe that one fundamental ingredient of the broader campaign to ensure that the need for palliative care for all individuals is taken seriously is the elimination of certain references throughout the Public Health Code to “intractable” pain and “terminally ill” patients.

Patients nearing the end of life due to an advanced illness must also deal with a wide array of other issues. For instance, people are increasingly availing themselves of opportunities to issue advanced directives indicating their preferences on specific end of life issues and to designate representatives authorized to make end of life decisions on their behalf. Advanced directives and designated representatives are only significant, however, if medical personnel know about them. Conversely, certain treatment options, such as hospice care, are available to patients nearing the end of life, but a patient, or his or her representative, will not request such options unless they know about them. Some people believe that steps should be taken to make it easier for medical personnel to ascertain patients’ advanced directives and designation of advocates and that health care personnel should inform patients of the availability of hospice care at the facility to which they are being admitted.

THE CONTENT OF THE BILLS:

House Bills 5256, 5257, 5259, and 5263-5265 were introduced as part of an “End of Life Care” package. The package also includes House Bills 5254, 5255, 5258, 5260-5262, and 5266, which remain under consideration by the Committee on Health Policy at this time. House Bill 5148 was introduced before the package but also deals with end of life issues. Specifically the bills would do the following:

House Bill 5259. Article 17 of the Public Health Code regulates health care facilities and agencies. Among other things, the article requires a health facility or agency that is licensed under the article, and that provides services directly to patients or residents, to adopt a policy describing the rights and responsibilities of patients and residents who are admitted to the facility or agency.

House Bill 5259 would amend this article (MCL 333.20201) to require such a policy to recognize that a patient or resident is entitled to adequate and appropriate pain and symptom management as a basic and essential element of his or her medical treatment. The bill would also revise various references to a “health facility or agency” to clarify which provisions applied to health facilities or agencies, generally, and which provisions applied to specific types of health facilities or agencies, such as nursing homes and homes for the aged. Further, the bill would clarify that a licensed health maintenance organization must comply with the Insurance Code of 1956 rather than with a section of the Public Health Code repealed in 1997. Finally, the bill would update certain references to the federal Social Security Act.

House Bills 5257. The Michigan Dignified Death Act, which is Part 56a of the Public Health Code, contains various references to “terminal illness” and “terminally ill patients.” Under the act, “terminal illness” is defined as a disease or condition due to which, in the opinion of a physician, a patient’s death is anticipated within six months after the date of the physician’s opinion.” House Bill 5257 would amend the Michigan Dignified Death Act (MCL 333.5656 et al.) to change references to “terminally ill” patients to patients who “have a reduced life expectancy due to an advanced illness.” The bill would also revise a requirement that the Department of Community Health develop and publish a standardized, written summary containing information specified in a provision that would be amended by House Bill 5258. (House Bills 5257 and 5258 are tie-barred, though House Bill 5258 remains under consideration by the committee at this time.)

Currently, the Michigan Dignified Death Act requires a physician to provide certain information to a patient (or representative) when recommending medical treatment for a patient who *has been diagnosed* as having a terminal illness. The physician must provide some of the required information orally. However, the physician must provide the rest of the required information both orally and in writing, and the Department of Community of Health was required to develop and publish a written summary containing this information by the end of May 1997, (i.e., within 60 days of the effective date of the act that added the requirement). Under circumstances described in the act, a physician may provide a copy of the summary to a patient instead of notifying the patient of his or her options.

House Bill 5257 would add a new report requirement that would have to conform substantially to the requirements for the earlier report. Specifically, the department would have to develop and publish a new summary containing the information that a physician would have to provide to a patient both orally and in writing. (House Bill 5258 would add a requirement that the physician inform a patient orally and in writing that he or she could choose adequate and appropriate pain and symptom management as an element of treatment, and the report would have to state this as well. Moreover, House Bill 5258 would amend the information requirement so that a physician would have to provide such information to those patients for whom the physician was recommending medical treatment, only if *that physician had diagnosed* the patient as having a reduced life expectancy due to an advanced illness.) The new report would have to be developed and published by January 1, 2002. The bill would continue to allow a physician to give a patient a copy of the department's summary instead of notifying the patient of his or her options orally and in writing.

The change to the provision of the act allowing a physician to provide a patient with a copy of the department's written summary instead of informing the patient of his or her options both orally and in writing would take effect on March 1, 2002. The other changes to the act would take effect on the bill's effective date.

House Bills 5263-5265. House Bills 5263-5265 would amend provisions of the Public Health Code, the Insurance Code of 1956, and the Nonprofit Health Care Corporation Reform Act, to eliminate definitions of and references to "intractable" pain. Specifically, the bills would do the following:

House Bill 5263. Article 15 of the Public Health Code regulates health care occupations. Among other things, the article provides for the creation of a committee with certain responsibilities regarding pain and symptom management. The bill sets forth requirements for the composition of the committee, including a requirement that the committee include one registered professional nurse, one dentist, one pharmacist and one physician's assistant, all of whom must have training in the treatment of "intractable" pain. House Bill 5263 would amend Article 15 (MCL 333.16204a) to eliminate the requirement that these four members have training in the treatment of intractable pain, specifying instead that they had to have been trained in the treatment of pain.

House Bill 5264. Chapter 34 of the Insurance Code of 1956 regulates disability insurance policies and Chapter 36 of the code regulates group blanket disability insurance policies and family expense insurance policies. Chapter 22 of the code currently requires that an insurer that delivers, issues for delivery, or renews in this state an expense-incurred hospital, medical, or surgical policy or certificate issued under Chapters 34 or 36 provide a written form to an insured person upon enrollment. The form must describe the terms and conditions of the insurer's policies and certificates. Currently, the form must describe how the covered benefits apply in the evaluation and treatment of "intractable" pain, among other things. House Bill 5264 would eliminate the reference to intractable pain, specifying instead that the form had to describe how the covered benefits apply in the evaluation and treatment of pain. The bill would also eliminate the reference to intractable pain in a provision that allows individuals covered by such policies or certificates to request a description of the professional credentials of participating health professionals, including those who are board certified in the evaluation and treatment of intractable pain. Instead, a covered insured could request information on the professional credentials of participating health care professionals, including those who were board certified in the evaluation and treatment of pain.

House Bill 5265. The Nonprofit Health Care Corporation Reform Act requires, among other things, that a health care corporation provide a written form to subscribers upon enrollment that describes the terms and conditions of the corporation's certificate. Like the form described above, this form must describe how the covered benefits apply in the evaluation and treatment of "intractable" pain. House Bill 5265 would eliminate this reference to intractable pain, specifying instead that the form had to describe how the covered benefits applied in the evaluation and treatment of pain. Like House Bill 5264, the bill would also revise a provision that allows members for certain offered services to request a description of the professional credentials of participating health professionals, including those who are board certified in the evaluation and treatment of intractable pain. Instead, members could request a description of the professional credentials of participating health professionals, including those who were board certified in the evaluation and treatment of pain.

House Bill 5256. Part 217 of the Public Health Code provides for the licensing and regulation of nursing homes. Among other things, the code requires a nursing home to execute a written contract with an applicant or patient at the time an individual is admitted to a nursing home and at the expiration of the term of a previous contract. Alternatively, a nursing home may execute a written contract with the applicant's or the patient's guardian or legal representative who is authorized by law to have access to those portions of the patient's or applicant's income or assets available to pay for nursing home care. House Bill 5256 would amend this part of the code (MCL 333.21766) to add a requirement that a nursing home notify applicants or patients of the availability of hospice care in the nursing home before executing the written contract.

Specifically, the bill would require that the nursing home provide written notification to a patient or applicant or his or her guardian or legal representative of the availability or lack of availability of hospice care in the nursing home. The written notice would have to be provided in a specific paragraph located in a written contract, and that paragraph would have to be signed or initialed by the applicant, patient, guardian, or representative before the execution of the written contract. If the nursing home failed to comply with this requirement, the contract could be rendered void at the option of the patient, guardian, or representative.

Currently, the written contract must specify the term of the contract and the services, and charges for services, to be provided under the contract, among other things. The bill would require that the written contract specify the ability of the patient or the patient's guardian or legal representative to void the contract under specific circumstances. Also, the bill would specify that the written contract had to set forth the services (and charges for services) to be provided under the contract included the availability of hospice or other special care.

"Hospice" would mean "a health care program that provides a coordinated set of services rendered at home or in outpatient or institutional settings for individuals suffering from a disease or condition with a terminal prognosis."

House Bill 5148. The Michigan Vehicle Code charges the secretary of state with issuing operator's and chauffeur's licenses (i.e., driver's licenses) to qualified applicants. House Bill 5148 would amend the vehicle code (MCL 257.310) to allow a license to contain a statement that the licensee carried an emergency medical information card or to contain a sticker or decal indicating that the licensee had designated a patient advocate. The emergency medical information card could contain the licensee's emergency contact information, information concerning the licensee's patient advocate designation, other emergency medical information, or an indication as to where the licensee had stored or registered emergency medical information.

The sticker or decal indicating that the licensee had designated one or more patient advocates, in accordance with the Estates and Protected Individuals Code, would have to meet the secretary of state's specifications. Any person, hospital, school, medical group, or association interested in assisting in implementing the emergency medical information card could provide the sticker or decal.

BACKGROUND INFORMATION:

In August 2001, the Michigan Commission on End of Life Care, responding to an executive order issued in 1999 (and extended in 2000), presented its final report to the governor. The twelve-member commission represents a broad spectrum of the health care profession, including doctors, nurses, social workers, administrators, lawyers, a professor of spirituality and ethics in medicine, a professor who serves as the director of a palliative care education and research program, two directors of state executive departments, and a state representative. Among other things, the commission was charged with issuing policy recommendations "with respect to end-of-life care, including examining and compiling the best ideas of multiple groups currently engaged in examining end-of-life issues and considering these in the development of the Commission's final report." These bills, which reflect not only the commission's work, but also the input of members of a workgroup consisting of various other members of the health care industry who were not members of the commission, are part of a larger package of bills and resolutions dealing with end of life care issues.

FISCAL IMPLICATIONS:

According to the House Fiscal Agency, House Bills 5256, 5259, and 5263-5265 would have no fiscal impact on either the state or on local units of government, and House Bill 5257 would have a negligible fiscal impact on the state or on local units of government. (10-23-01)

The House Fiscal Agency reports that House Bill 5148 could require the secretary of state to reformat operator's and chauffeur's licenses to accommodate a label, decal, or statement, and the cost projection for reformatting the licenses is indeterminate at this time. (10-22-01)

ARGUMENTS:

For:

House Bills 5263 – 5265 would revise certain references to "intractable pain" to "pain." House Bills 5257-5259 would establish a patient's right to adequate pain and symptom management. According to the governor's end of life care commission, "the lack of effective pain and symptom management is a public health issue that requires the highest level of professional and regulatory attention." The focus in current law on pain that is "intractable" seems to suggest that some forms of pain are more *worthy* of being treated than other forms of pain. Pain is an elusive and irreducibly subjective phenomenon, which has befuddled some (otherwise intelligent) philosophers enough to try to solve rarified epistemological conundra such as whether two people can ever be assured that they mean the same thing when they say that they are in pain. Doctors and dentists employ clear, proven techniques for determining whether patients have broken bones or cavities. When they ask their patients how badly their broken bones and cavities hurt though, they resort to asking patient's questions such as, "on a scale of one to ten, how bad is the pain?" Based on their own experiences, no one would dispute the claim that some pain is more severe than others. At the same time, no one is suggesting that medical professionals ought to address the pain caused by a paper cut with the same urgency that they would treat the pain caused by a broken rib. The crucial point is that the fact that someone may be experiencing "relatively minor" pain should not be used to dismiss that pain as insignificant. The current law's focus on "intractable" pain—i.e., pain that is not easily alleviated—is "symptomatic" of the more general expectation that medical professionals must solve all problems, no matter how difficult. Health care providers and their patients should acknowledge the value of such victories, rather than always expecting medical professionals to be able to cure all problems.

For:

House Bill 5257 would revise references to "terminally ill" patients to "patients with a reduced life expectancy due to an advanced illness." One of the recommendations of the governor's end of life care commission was to promote "caring conversations" regarding end of life care issues between individuals and their loved ones. Revising these references paves the way for switching the focus of such conversations from thinking about imminent death to considering how to improve the quality of the life that remains. Doctors may feel more comfortable with diagnosing their patients as having a reduced life expectancy than they do diagnosing their patients with a terminal illness. No less importantly, patients may have an easier time confronting end of life care issues if they can think of them in terms of quality of life, rather than in terms of death and dying. House Bill 5258 would require doctors to inform patients that they may choose adequate and appropriate pain and symptom management as a basic and essential element of medical treatment. (Again, House Bill 5258 remains under consideration by the committee at this time.) House Bill 5257 would require the Department of Community Health to publish a new report that reflects this acknowledgement of this right of a patient, and doctors could provide a copy of the report to their patients, in lieu of informing them both orally and in writing. This too would promote patient's awareness of end of life care issues before the actual end of life.

Response:

If the desire is to promote "caring *conversations,*" perhaps the bill should require that a physician *orall*y notify his or her patients of their right to pain and symptom management. Also, by removing references to "terminally ill" patients, as would House Bills 5257 and 5258, and by eliminating the definition of "terminal illness" from the Michigan Dignified Death Act altogether, as would House Bill 5258, the bills could unintentionally give guardians of persons with certain disabilities inappropriate power. Perhaps the definition of terminal illness should be revised so that it would require a "diagnosis of an illness that had predictably fatal progression that could not be stopped by any known treatment," or something similar. This would avoid the reference to a definite six month time frame, as does the language proposed by the bills, but would more effectively realize the intent that this bill not give guardians of persons with certain disabilities inappropriate power.

Reply:

The revision of references to "terminal illness" to "having a reduced life expectancy due to an advanced illness" would not explicitly give guardians of persons with disabilities any additional power.

For:

House Bill 5256 would require nursing homes to notify prospective patients of the availability of hospice care at the nursing home. Nursing homes have an obligation to keep patients—whether present or prospective—apprised of end of life care issues and options. Many patients who are nearing the end of the life do not take advantage of hospice care early enough for such care to make a significant difference in their "quality of life." Part of the problem arises from the fact that Medicare patients, for instance, are only eligible for hospice care coverage if they are certified as terminally ill and as having a life expectancy of less than six months, and doctors may be hesitant to diagnose a patient as having such a short life expectancy. (Blue Cross and Blue Shield of Michigan and Medicaid have similar time specifications, though they allow for extensions.)

Still, a major problem is that patients do not know enough about hospice care. People entering nursing homes should be encouraged to think about end of life care issues, and hospice care may significantly improve the quality of life of a patient who is nearing the end of life. The availability of hospice care may be a significant factor in a patient's decision about whether to enter a specific nursing home. Also, a patient who knows that hospice care is an available option and a doctor who knows that a patient knows about hospice care may find it easier to broach the subject of end of life care issues.

Response:

Although the goal of promoting the use of hospice care as a means of enhancing the quality of life near the end of life is commendable, the bill would allow a patient who was not informed that hospice care was (or was not) available prior to signing the contract to render the contract void. This is too harsh and should be eliminated. The point of the requirement is to facilitate thinking about and discussing options between patients, their friends and family, and their health care providers.

Reply:

The bill needs to contain some strong provision encouraging nursing homes to comply with the requirement or the requirement may not be taken very seriously.

For:

House Bill 5148 would allow an individual to indicate on a driver's license that he or she had designated a patient advocate or that he or she carried an emergency medical information card. It is extremely important that medical professionals be able to act in accordance with an individual's expressed wishes concerning end of life care. It is increasingly common for people to discuss such matters with their close friends and family and indicate their preferences in anticipation of a situation in which they are alive but incapable of stating their preferences—e.g., they are unconscious, senile, or legally incompetent. Nevertheless, if a health care professional does not know that a patient has designated an advocate or issued an advance directive, the designation or directive will be ineffective. A driver's licenses is perhaps the most common piece of identification and the most easily recognizable form of identification that people carry. By allowing people to indicate that they have expressed preferences related to end of life care issues on their driver's licenses, the bill would encourage individuals to exercise the option and direct medical personnel to look for patient's driver's license, when treating a patient who was unable to speak or write. This would help ensure that a patient's wishes are followed.

Response:

One unintended consequence of allowing people to indicate that they have expressed such preferences on a driver's license may be that medical personnel who do not, for whatever reason, look for or find a person's driver's license could be held liable for forgetting or failing to do so. Medical personnel are already under a great deal of pressure in such situations, and it would be wrong to add to this pressure.

Reply:

Although it is hoped that medical personnel will look for a patient's driver's license, the bill contains no suggestion that they could be held liable for forgetting or failing to do so.

POSITIONS:

The American Cancer Society, Great Lakes Division, Inc. supports the bills. (10-23-01)

Right to Life of Michigan supports the bills. (10-23-01)

Ascension Health supports House Bills 5256, 5257, 5269, and 5263-5265, but does not have a position on House Bill 5148. (10-23-01)

A representative from the Michigan Health and Hospital Association indicated support for the End of Life Care package. (10-23-01)

A representative from the Michigan State Medical Society indicated support for the End of Life Care package. (10-23-01)

Analyst: J. Caver
