

**State Advisory Council on Quality Care at the End of Life
Minutes from the February 12, 2016 Meeting**

Meeting time and place: February 12, 2016, 10:00 a.m, Office of Health Care Quality, 55 Wade Avenue, Spring Grove Hospital Center, Bland Bryant Building, Catonsville, Maryland.

Council members present: Ted Meyerson, Chair; Paul Ballard (Attorney General's designee); Rabbi Michael Safra; Stevanne Ellis (Department of Aging's designee); Tricia Nay (Department of Health and Mental Hygiene's designee); Gail S. Mansell; Sister Lawrence Mary Pocock; Gail Amalia Katz; Karren Pope-Onwukwe; Hank Willner. On speakerphone: M. Jane Markley; Steve Levenson

Others present: Alan Eason; Frederick G. Weinstein; Anya Naegele; Sally Hunt; Elena Boisvert; Yvette Rode; Brendan Loughran.

Chairman Ted Meyerson convened the meeting at 10:00 a.m.

The Council discussed House Bill 404, which identical bill has also been cross-filed in the Senate as Senate Bill 418. House Bill 404 would allow a patient to request "aid in dying," defined in the bill as "the medical practice of a physician prescribing medication to a qualified individual that the qualified individual may self-administer to bring about the qualified individual's death." Chairman Meyerson asked members to comment on the bill.

Elena Boisvert, an elder law attorney appearing at the Council meeting on behalf of Council member Catherine Stavelly, stated her concern that in her experience senior clients she counsels often ask their sons and daughters for feedback and can be subject to undue influence from their family members who may be financially exploiting them. Seniors can also be vulnerable to subtle influence from family members, which may mean that the decision to choose aid in dying may not be always be an independent judgment. She noted that undue influence can be very difficult to prove. While she acknowledged that the bill provides for criminal penalties for undue influence, she would also like to see preventative measures included in the bill. She recommended that the bill at the very least require a mental health screening by a geriatric psychiatrist who would understand what undue influence is about to help to prevent coerced decisions.

Hank Willner stated his belief that the bill would be harmful to the medical profession and would make a lot of patients nervous about the role of the doctor. He stated that if people want to end their life, there are many ways to do that they can be found on the Internet and that physicians do not need to be involved.

Rabbi Mickey Safra acknowledged the pain and the difficulties that is involved in some of these cases but stated his concern about the bill's requirement that a physician give a prognosis that the patient is likely to die within 6 months because of the difficulty in making that judgment. He also stated that 6 months is an arbitrary marker that puts suffering for the last 6 months of life in a different legal category than suffering for a much longer period before death. He also stated his concern that a physician could be accused of undue influence and would thus

be open to lawsuits from family members because the bill does not require family members be told about the prescription for the medication that would bring about the patient's death. He also stated his concern about the public perception that hospice care and palliative care can be equated with "death panels" and that it would make it harder for patients to distinguish between hospice care, palliative care, and aid in dying.

Sister Lawrence Mary Pocock stated while that she is against any form of assisted suicide, she also has particular concerns with this bill. First, a patient must meet the bill's definition of having "capacity to make medical decisions" in order to qualify for "aid in dying" but there is no requirement that a mental health professional such as a psychiatrist or psychologist make this determination. Therefore, there is not adequate protection to prevent a person with a mental disorder from receiving medication to self-administer to bring about their death when they might have regretted making that decision at a different time.

Hank Willner noted that unlike a competency determination, a capacity assessment that requires the application of several criteria does not have to be completed by a mental health professional. But he did not believe the description in the bill was adequate to describe the element of decision-making capacity. He noted that physicians who understand the criteria for determining capacity are capable of performing those assessments. Steve Levenson noted that many physicians do not understand the principles for assessing a patient's decision-making capacity. He noted that if a physician familiarizes themselves with the criteria to evaluate a patient's decision-making capacity, a mental health professional's opinion would not also be necessary. Tricia Nay noted that in her experience as a regulator she has observed that most physicians have not been trained in determining capacity and that there is not one standard to follow for determining capacity. For example, she stated that sometimes physicians don't understand that a patient can make bad decisions and still have the capacity to make health care decisions. It is a constant effort to educate health care providers regarding the proper way to assess a patient's capacity and it is crucial that they be given the tools to properly perform capacity assessments.

Karren Pope-Onwukwe noted that most people that she counsels rely on their faith tradition and their family members in making these decisions. She noted that the people who share the faith tradition she grew up with are not generally going to change their thinking regarding leaving life and death decisions to the will of God. Nonprofessional people are trying to make decisions to help their family members. The bill is asking these folks to change their way of thinking about these issues. She believes this bill is designed for a very small segment of the population and is not relevant to the population she counsels who deal with these issues of life and death.

Gail Amalia Katz stated that there is not a role for religion in whether this bill should become law. There is separation of Church and State. She stated that very good protections have been incorporated in the laws of other states. She is not aware of any abuse of similar laws in other states. Tricia Nay stated that only 5 other states allow aid in dying so the number for statistics would be small. Gail Amalia Katz responded that with the aging of the population, there will be more people who will want this option to be available. Gail Mansell stated that she

wished there could be another way but understands that it is one way for patients to assert control.

Steveanne Ellis noted that the bill does not mention suicide and wondered to what extent lawsuits have been filed with regard to failure to abide by advance directives. Paul Ballard stated that he did not believe there were many examples in case law because most of those instances would be at the trial level and would not result in published judicial opinions. Steveanne Ellis asked whether this bill was similar to what was being proposed in other states.

Steve Levenson stated he was impressed with the excellence of everyone's thoughts. He stated that it is not clear that all the relevant considerations have been adequately thought through in the bill. He noted that the enactment of laws such as the MOLST law, Health Care Decisions Act and the statute creating the patient care advisory committee did not result in every health care provider implementing these laws correctly despite the existence of the Health Care Decisions Act and the statute regarding the patient care advisory committee for many years. He stated that before the State passes more laws, the State should look first at executing the laws properly that already exist. He noted that hospice patients can sometimes get better when they are taken off of medications that made it appear they were more likely to die. Thus, it is difficult to come up with a reliable prognosis regarding a terminal condition. He also noted that lawsuits may not arise because people may not be aware there is a problem with the way the law has been complied with in a certain situation.

Jane Markley noted that the problem with the bill's definition of "palliative care" is that it is limited to a terminal ill patient when in fact palliative care may be appropriate when a patient is not terminally ill and such care may appropriately begin before the 6 months terminal condition prognosis begins. Steve Levenson noted that some patients who are referred to hospice must leave because it turns out that they do not die within 6 months. This complicates matters because even though they do not meet this definition of "terminal" they still need palliative care.

Tricia Nay noted that the Office of Health Care Quality would likely be responsible to adopt regulations and perhaps a 200-page book to provide guidance on implementation of the aid in dying law.

Jane Markley noted that an ALS patient may no longer be able to self-administer by the time the 6-month criteria for a terminal prognosis is met.

Tricia Nay noted with regard to potential implementation issues that as an example in the University of Maryland study the MOLST form has been accompanied by a note from the health care provider documenting the conversation with the patient or the authorized decision maker 94% of the time in one setting but only 42 % of the time in another setting despite all of the educational effort regarding the MOLST form. She stated it is crucial for proper implementation that there are safeguards and a clear process in the bill and the resulting regulations to guide health care providers.

Sister Lawrence Mary Pocock also expressed her concern that the bill only requires that the patient be counseled as to the importance of having someone with them when they self-administer but that it is not a requirement that someone be with the patient. She stated that this creates problems in case adverse events happened where the patient cannot finish the quantity required or if the patient changes their mind in the course of taking the medication, or something else happens that is unexpected. Also, if the patient takes it in a public place there is potential for a mass suicide but the bill does not require that the medication be taken in a private place. She does not believe the bill has sufficient requirements to prevent these potential adverse events from happening.

Hank Willner stated his belief that the bill's statement that the death would be as a result of natural causes is absurd. He stated there are currently 2 legal and ethical options to end life: (1) to stop eating and drinking which will usually cause death within a couple of weeks; and (2) the administration of palliative sedation when a patient is close to death. He stated that a patient should not be permitted to end their life simply because of existential angst.

Tricia Nay stated that palliative sedation has safeguards in that an interdisciplinary team (usually in a hospice setting) approves and continually revisits the issue to insure that it continues to make sense. There is an abundance of documentation in those cases that she has reviewed.

Hank Willner stated that there is the option of respite sedation and that sometimes patients will decide to carry on with life after receiving respite sedation.

Gail Mansell stated she has a problem with almost every definition in the bill. She asked whether we are to assume that people are already diagnosed with a terminal condition. Steve Levenson responded that terminality can be an aggregate of a lot of things going on with the patient and that this bill presumes that there is a discrete cause that will result in imminent death. This prognosis is more difficult to make when there are an aggregate of conditions that will lead to death and when there are treatments available that might improve the patient's prognosis.

Hank Willner noted that physicians are better at making a prognosis of a few weeks rather than 6 months because patients do often improve in hospice and can graduate.

Ted Meyerson stated he was talking on behalf of the general population which he believes generally support the bill. He stated he knows of no one who has not known someone who has suffered before death. Physicians are charged to do no harm. Theologians are charged to preserve life. Less than 200 people out of 2,000 people in Oregon given the prescription to end their lives take advantage of the option. He mentioned the young woman in California that moved to Oregon to take advantage of their law to give her this option because she did not want to die in pain. He stated that last year he voted against the bill because he was concerned that the 6-months terminal prognosis was not an accurate requirement. But he noted that this law has not proven to be an issue in other states and he does not believe it will be an issue here. He stated that he wants to have the option of aid in dying and will vote in favor of supporting the bill.

Rabbi Mickey Safra stated that he is approaching the issue as a pastor that works with families, not as a theologian. He stated that the bill incorrectly assumes that patients now have no choices regarding when they wish to die. He believes that the bill creates a false distinction between what occurs now and what the bill would permit.

Gail Amalia Katz stated that she suffered through dealing with a family member's ALS and that she has suffered from chronic pain. She stated her belief that the option for aid in dying removes anxiety and provides a tremendous comfort for people.

Ted Meyerson asked that each Council member vote to support or not support the bill and that Council members not present should be contacted to get their position.

Alan Eason stated that he appreciated the Council members' nuanced comments and that simply recording a vote would not adequately reflect the depth of the Council members' discussion of the issues. He asked the Council not to vote on the bill.

Elena Boisvert suggested that the Council has an opportunity to present its thoughts in writing to the legislature explaining its position and that written position would be included in the bill's legislative history. Paul Ballard agreed that would be useful for the legislature. Steve Levenson agreed to summarize the Council members' thoughts in a report. The Council was in general agreement regarding their desire that a report be generated as written testimony to the legislature. A draft will be prepared by Paul Ballard and Steve Levenson and emailed to Council members for their review. Council members not present will be shown the draft and asked for their input and to add their thoughts regarding the bill.

The following Council members were in favor of the bill: Ted Meyerson and Gail Amalia Katz. The following Council members were opposed to the bill: Hank Willner; Sister Lawrence Mary Pocock; Karren Pope-Onwukwe; Jane Markley; Rabbi Mickey Safra; and Steve Levenson.

No further items of business being presented, Chairman Meyerson adjourned the meeting.