

State Advisory Council on Quality Care at the End of Life
Minutes from the February 8, 2019 Meeting

Meeting time and place: February 8, 2019, 10:00 a.m., Office of Health Care Quality, 7120 Samuel Morse Drive, Second Floor, Columbia, MD 21046-3422

Council members present: Alan Eason, Chair; Paul Ballard (Attorney General's designee); M. Jane Markley; Tiffany Callender; Yvette Oquendo-Berruz; Christian Miele (Department of Disabilities' designee); Karen Smith; Tricia Nay (Department of Health's designee); Carol Eckerl; Christine Watts; Sister Lawrence Mary Pocock; Christopher Kearney; Elena Sallito Boisvert; Marian Grant. On speakerphone: Michele Williams; Jocelyn El-Sayed; Stevanne Ellis (Department of Aging's designee).

Others present: Therese Hessler; Sally Hunt; Jack Schwartz; Anita Tarzian; Harold Bob. On speakerphone: Tim Cox.

Chairman Alan Eason convened the meeting at 10 am.

The Council discussed House Bill 399 and Senate Bill 311. Paul Ballard briefly summarized the identical cross-filed bills' provisions that would authorize aid in dying, that is, a self-administered medication prescribed by a physician to a qualified individual at the individual's request, which medication would bring about the individual's death. Alan Eason noted that information sheets about the bills prepared by Compassion and Choices, an organization that supports the bills, were available at the meeting for the Council members' information. Sally Hunt stated that except for the title, the bills were the same as the prior versions introduced in previous legislative sessions.

Alan Eason noted that prior to serving on the Council he had been active in Compassion & Choices. Because he is now Chair of the Council, he said he is not now actively involved with that organization in order to avoid any conflict of interest. He noted that in 2017 the Council had voted on taking a position on similar bills. He reiterated his belief stated at that time as a citizen guest at the Council meeting that given the bills' complexities it is not appropriate for the Council to vote on such bills, especially considering that a quorum of the Council consists merely of those Council members who attend the meeting.

Carol Eckerl asked whether the Council was mandated to comment on the bills. Paul Ballard advised that commenting on such bills is part of the Council's statutory mission and the Council may do so if the Council believes they are important to comment upon. Alan Eason noted that the Council's authorizing statute states that the mission of the Council includes advising the General Assembly on legislative proposals affecting the provision of care at the end of life.

Christian Miele suggested that the Council could provide the legislature with a letter of information to express the Council's perspectives and concerns. He stated that there is an Equal Protection concern with the bills because some disabled individuals are not able to write or use

their limbs. Therefore, they may not be able to avail themselves of the medication because they would not be able to provide a written request to their physician for a prescription or be able to self-administer the medication as required by the bills' provisions. He stated the Council may want to inform the legislature of the constitutional challenges that could arise from this issue.

Elena Sallitto Boivert stated that the bills provide insufficient safeguards to protect seniors from financial exploitation. She said that an individual's capacity to make health care decisions is fluid. She asked at what point is an individual able to consent to aid in dying and at what point are they going to be unduly influenced. She stated that to be subject to undue influence an individual must have capacity, that is, you can't be incompetent and be unduly influenced to do something. She noted that only one of the required witnesses to the individual's written request for aid in dying may not inherit from the individual. For example, she stated that a greedy daughter who wants to hasten her mother's death could pressure her mother to sign a written request with only a paid caregiver as a witness to the written request. She said she heard that the medication is quite a substantial cocktail that is suggested to be downed with a bottle of scotch or something comparable. She would like to see a health care provider present when the medication is self-administered because you don't know what is going to happen, for instance, will the person be able to take it, will they throw up, or will there be issues when they are *in extremis*. She also expressed her concern that a senior may be susceptible to being talked into taking the pill at a certain time of day. She is not opposed to the bills from a moral point of view but sees potential problems. Finally, she stated there are not sufficient safeguards in the bills.

Marian Grant said that 7 States, Canada, and the District of Columbia have authorized aid in dying, some of which have done so for 20 years. She said that she and Christopher Kearney went to a two-day workshop on these issues conducted by the National Academies of Sciences, Engineering, and Medicine ("National Academies of Sciences"). She stated her understanding that in California there has to be a mental assessment of every person who requests aid in dying, and that the assessment must evaluate for depression as well as for capacity to make health care decisions. She noted that people from California at the workshop stated that this was a great idea in theory but difficult to execute in practice. She wondered whether these bills are similar to the laws in these other states. She asked what the reality is in the other states that authorize aid in dying. Elena Sallitto Boivert responded that it would be impossible to know because if you're a financial exploiter, this is a beautiful law because you're hastening the death of an ill person by a few months rather than killing a healthy person. Marian Grant stated that if there is financial exploitation that results from this, it would be helpful to know, although she acknowledged it may not be possible to know. She noted that these laws have been in existence for a long time.

Harold Bob stated that physicians are not accurate as reflected in published studies (in prognosis of end of life residual life expectancy) of estimating the time a patient has left to live. He said that the required hospice benefit prognosis made by physicians of 6 months left to live, has an error rate of 15 % (that is, the patient lives longer than 6 months) and that the error rate for non-hospice patients who don't have a hospice physicians is 4 to 6 times that rate according to the National Institutes of Health. He said the 20 or so patients he had seen in his medical practice who had asked for his help to die (which he did not provide) were either afraid of pain or afraid that their advance directives won't be honored. He also said that he has promised these patients that they will not be in pain and that their advance directives will be honored. He said they all

have trusted him to do what he said. He said in his experience that after compassionate extubation was performed at the hospital, 10-15 % of patients died within an hour and 90% died within the first day. He said physicians have to be skilled to avoid bad deaths. He noted that things don't always go as expected as sometimes occurs in executions. Christopher Kearney said compassionate extubation should not be associated with executions, noting that in contrast to executions, compassionate extubation is performed to remove a patient from non-beneficial life support when the patient is already dying from natural causes.

Marian Grant asked what the evidence says about the issue. She asked whether people are reporting horrible deaths with the recommended dosages and regimens used in aid in dying. For this purpose, she said there are prescribed dosages and thus the variability of physician's skills is not the same issue. She noted that sometimes there have been reports that death did not result as quickly as anticipated.

Christopher Kearney said that the American Medical Association has not taken a position and that the Hospice and Palliative Care Network's board has not taken a position. He said that there may be language that the Council could consider that is used by these organizations.

Sister Lawrence Mary Pocock reminded the Council of her strong moral and ethical opposition to assisted suicide. She also said that there were other problems with the bills. She said the bills do not provide for proper education on how to take the drugs. She said there is no provision in the bills regarding the disposal of the drug if the person has taken a little bit of it or has changed their mind completely. She noted there is already a huge problem with opioids and that these bills would create another one. She said that anybody could get hold of the medication, that there is no identification requirement to get the medication, and that it could be used for a criminal purpose. She also stated her concern that the person taking the medication would be alone and that if it doesn't go well and they change their mind, there is no one there to help. Or perhaps there will be someone there to force them to finish it, which would certainly not be helpful to the person. Finally, she stated her concern that the bills would require that the death be deemed to be the result of natural causes when it is not. She stated that the person would die because they took the medication for the purpose of ending life. She noted the bills state that the actions relating to self-administering medication "do not constitute... assisted suicide" and questioned how aid in dying is different from assisted suicide. She said the word "assisted" means to help and that "suicide" means to take one's life. She stated it can be called aid in dying but it is in fact assisted suicide.

Elena Sallitto Boisvert stated she has testified against these bills several times in past years and wondered why it keeps staying in the same format without taking into account such legitimate concerns as those expressed by Sister Lawrence Mary Pocock, those about financial exploitation, and those regarding how the bills would apply to persons with disabilities. She wondered why the bills' sponsors have not addressed these legitimate concerns and she stated that it is not a serious legislative discussion.

Alan Eason said these laws have been in place for 20 years or so in other states like Oregon and Washington, and that they have experiences in these states and they have statistics. He stated

that there is a relatively small percentage of persons who actually take the medication. He stated that people have religious and philosophical differences.

Elena Sallitto Boivert stated that Maryland does not have a history of tracking the legislation of other states. As an example, she noted that Maryland's MOLST law is different than the rest of the country's laws regarding standard medical life-sustaining treatment order forms. She stated that Maryland has a unique perspective and should not necessarily listen to other states.

Christopher Kearney stated that MedStar DC was required to come to some determination about this issue. The palliative care staff of MedStar were asked for their opinion on the issue. He stated that people believe that physicians perform aid in dying anyway, so it is important there be a bright line drawn distinguishing hospice/palliative care from aid in dying. Although MedStar's board of medicine did not arrive at a conclusion regarding aid in dying, the board did conclude that no one should be requesting it because there exists a lack of good palliative care services. He said that most people in Oregon who use this option are in hospice care already. He noted that no physician or health care system is required to participate. He stated that under the bills that the second physician is loosely defined and could be a partner of the attending physician. He suggested that perhaps there could be an expert panel that would review requests for aid in dying, as is the case in Europe where they have standards for how they would go about this. He said a more standardized process would make sense. He stated the Council needs to make some recommendation to the legislature even though the members won't agree. He said that something the Council could agree on would be the need to look at improving access to palliative care services across the State of Maryland.

Jack Schwartz suggested that the Council frame any communications to the legislative committees in terms of how the Council could be helpful to the legislature and noted that it would not be helpful to the legislative committee to simply say the Council voted 8-7 regarding whether it supported the bills. He said that the Council could be helpful by identifying things that the legislative committee would want to take into account. He said the Council could focus on things it could speak to in an authoritative way, for example, the overriding importance of the effectiveness of palliative care.

Alan Eason said that we have far to go in palliative care and in the education of patients and physicians. He noted there could be any number of things that would affect the perspectives of physicians. He said that some people may misperceive palliative care as giving up. He said there should be a focus on the availability of, and access to, palliative care and hospice care.

Anita Tarzian said priority should be given to ensuring that health care providers can access advance directives to carry out the treatment wishes stated by a patient. She talked about her experience as a patient at a hospital. She told the hospital pre-op staff she had a copy of her advance directive in CRISP ("Chesapeake Regional Information System for Our Patients", Maryland's designated health information exchange). She said the staff made her say she did not have a copy of her advance directive because they did not think they had access to it on CRISP. She had used MyDirectives.com to prepare her advance directive online. Then the nurse practitioner went onto CRISP and at first said she did not have access to it but after Anita

Tarzian insisted she did have access, the nurse practitioner said “Oh, yes, we do. That’s so cool. I’m going to tell others.” Anita Tarzian stated awareness of this capability on CRISP is lacking.

Harold Bob said he never feels he is giving up when he provides palliative care services because he is strictly applying evidence-based medicine. He noted that hospice patients with Stage 4 disease on average lived 27 more days than other patients. Marian Grant responded that Council members are very supportive of palliative care. Alan Eason stated that there are some primary physicians who won’t talk to their patients about palliative care services and hospice care services when they should.

Marian Grant referred to Christopher Kearney’s statement that most patients who choose aid in dying in Oregon are already in hospice care. She said she wants to make palliative care available to everyone with serious illness in Maryland from diagnosis onward but that for some patients that is not enough. These patients don’t want to lose their independence and become a burden on their families. All she has been able to say to patients is to stop eating, which is hard on the family. She said that excellent palliative care and hospice care is still not going to be enough for some people who want the option of aid in dying. She noted that whether they should have that option is the big debate.

Elena Sallitto Boisvert said that she would like the options of “palliative care when appropriate” and “hospice care when appropriate” added to the State advance directive form. Carol Eckerl said she saw an advance directive prepared by an attorney in Texas in which the person had requested all life-sustaining treatment be provided but stated in parentheses “except if I am in hospice care.” Paul Ballard noted that Maryland’s statutory advance directive form on the Attorney General’s website is optional to use, that other forms may be used, and that any changes to the statutory advance directive form would require legislation.

Christian Miele suggested that the Council provide a letter of information to the legislative committees because the Council as an expert body could be helpful to the legislature.

Therese Hessler cited California Department of Health statistics that stated that in 2016, 250 people in California started the process, 191 people were prescribed the medication, and 58% of those people took the pills and died, then in 2017, 632 people started the process, 577 people were prescribed the medication, and 62% of those people took the medication and died. She noted that the medication used in California is a Schedule III barbiturate that was banned in Maryland in the 1970’s.

Alan Eason stated that while the Council’s issue spotting is good, that it would be difficult for the Council to comment and to come to an agreement at the meeting. Marian Grant asked whether the Council would want to work on this issue to be ready to comment in a future legislative session. Paul Ballard asked whether there is anything regarding this issue about which the Council is unanimous.

Alan Eason stated that the Council should not vote on the bills. He stated the Council will have minutes and can reexamine this issue if necessary. If the bills are reintroduced next session, he said the Council could reexamine them then.

Jack Schwartz noted that the bills could end up on the Governor's desk and the Council may want to have something prepared to say to the Governor.

Elena Sallitto Boisvert stated that the committees should form a subcommittee to study the issue in depth. She said the subcommittee could look at statistics from other states where assisted suicide is authorized and look at Europe's experience with expert panels, including why they believed them to be necessary, and their effectiveness. She stated that if Maryland is to authorize assisted suicide, then we should have full knowledge of what everyone's experience was. At that point, the Council could then provide a statement to the Governor.

Marian Grant suggested that Council could send the legislative committees the report prepared by the National Academies of Sciences. Elena Sallitto Boisvert agreed.

Sally Hunt stated that the National Academies of Sciences report is excellent and that things have happened since the report was published. She stated that the American Academy of Physicians is now neutral on the issue and believes assisted suicide is not the appropriate term. She stated that Oregon has the best palliative care and hospice care in the country because Oregon has this law and started to address hospice and palliative care when the law was enacted.

Christopher Kearney stated that the Council could agree that no one should be requesting aid in dying for lack of robust palliative care services and noted that Maryland has a long way to go in that regard. He stated that good palliative care resources would lead to a resolution for a lot of these patients, although for a small number of patients that would not be sufficient for them.

Christian Miele quoted from the Council's authorizing statute as follows: "The Advisory Council shall advise the General Assembly on legislative proposals affecting the provisions of care at the end of life." He stated that the Council would be abrogating its duties if it did not at least share its thoughts with the legislature. Otherwise, it would not be serving the public good. He stated that the Council can offer expert advice and insights to help the legislators in their consideration of the nuanced issues in the legislation, including error rates for prognosis regarding the length of time a person has remaining to live. He said the Governor might ask why the Council did not advise the legislature. Christian Miele stated that even sharing the Council minutes with legislators would be great.

Jane Markley said the Council should provide a statement to legislators containing issues for their consideration that would highlight what the Council discussed. Sister Lawrence Mary Pocock suggested sending a letter to the legislative committees based on the Council's minutes. Marian Grant said the letter could state that the Council met and discussed the bills, state some of the concerns that were raised, and state that the Council is unanimous in its support of access to quality palliative and hospice care. Jane Markley suggested that it be clarified that both inpatient and outpatient palliative care be included in that statement. Marian Grant said she emailed to Paul Ballard the National Academies of Sciences report for him to forward to the legislators.

Sister Lawrence Mary Pocock noted that the need for palliative care doesn't begin at the time of death or shortly before death but that such care should begin at the time of diagnosis.

Tricia Nay suggested that the Council send to the committees a shorter document of bullet points for consideration based on the Council's discussion. Alan Eason suggested that the Council's letter to the committees include matters to think about, including the link to the National Academies of Sciences report.

Tiffany Callender suggested that the Council prepare white papers anticipating issues, so that as legislation is introduced in the future, the Council will already have white papers prepared.

Alan Eason suggested that the letter to the committees include a synopsis of issues and links to websites that provide information.

Christopher Kearney discussed the Coalition to Improve Serious Illness Care in Maryland. He said palliative care is a newer specialty done primarily in hospitals. He said that throughout the country there is general agreement that these services need to be provided in the community rather than in hospitals. He said that some states, and California in particular, have gotten way out in front on this issue and have recognized that this is not just a medical issue but that everyone has an interest in serious illness care in the State of Maryland. The Hospice and Palliative Care Network of Maryland has partnered with the Coalition. He stated that he and Tim Cox are co-chairs of the Coalition's steering committee. He noted that the Compassionate Care Coalition of California has been around for 10 years and Maryland can benefit from their experience. A year ago California mandated that all its 13 million MediCal patients get a palliative care benefit similar to the Medicare hospice benefit. He said that CareFirst has a similar palliative care benefit for its members in Maryland, in the District of Columbia, and Virginia. He also said the District of Columbia CareFirst has a good benefit. Finally, he said that the Coalition will identify resources that are available in Maryland.

Marian Grant, who is on the Coalition's steering committee, said any interested party can join, and there are opportunities for individual membership and low prices for organizational membership. She said Massachusetts had 80 organizations sign on to be part of their coalition. She stated that the Coalition could decide what workgroups would be formed and the people involved can determine what they want to do, perhaps including an annual conference. She wondered whether the Council could support the Coalition. She said she is in the process of getting the Coalition codified and getting a website up and running in the next couple of months. She also said CareFirst offered its offices throughout Maryland for listening sessions to see what organizations might wish to join, such as advance care planning organizations, hospice organizations, and family caregiver groups and patient advocacy groups. She said that so far the Coalition has met with the Maryland Hospital Association and CareFirst.

Paul Ballard asked whether the Coalition is asking the Council to support the Coalition's mission. Marian Grant said she could share information with the Council so that it could see what it would be endorsing.

Jane Markley suggested that the Coalition give the Council standard updates at each meeting. Alan Eason agreed.

Harold Bob said there must be palliative care to reduce the 30-day return to hospital rate under the Medicare Waiver agreement.

Marian Grant talked about a Journal of the American Medical Association article titled “Rehabbed to Death” and said she would provide a link to Paul Ballard to send to the Council. She said the article was about frail elderly people being sent to a nursing home for rehab and ending up being trapped in a nursing home and cycling back and forth between a nursing home and a hospital.

Harold Bob said there is a need for palliative care for nursing home patients on dialysis based on the high return to hospital rate for these patients. Marian Grant said everyone made money on that in the old system. She said that is going to shift with the total cost of care. She said the challenge now is getting the palliative care infrastructure in place so that the new demand for palliative care services can be met.

Tiffany Callender asked for clarity regarding the Coalition’s mission. Marian Grant responded it is to improve care of Maryland residents with serious illnesses.

Alan Eason asked what the biggest factor was in contributing to the failure to have palliative care accessible. Marian Grant responded that payment is the biggest factor. She stated there is no sense in educating Marylanders about the benefits of community palliative care when there is no availability of palliative care services outside of some hospitals. She said once there is payment available for palliative care, then there will be a workforce issue. She said that simply raising awareness of the importance of palliative care will not solve the problem.

Christopher Kearney said that alternative payment models are now coming out, for example, that California is allowing hospice care programs to see patients who are not hospice certified, that is, who have a prognosis of living 6 months or less and who agree to give up curative care. He said that every hospice in Maryland is very interested in that approach.

Marian Grant said that hospices that have patients for too long have been considered by government agencies to be potentially fraudulent. Thus, she said that hospice care programs are appropriately nervous about providing services longer than 6 months because they have to explain why the 6-month prognosis was incorrect.

Jack Schwartz said that the Council might serve a useful purpose as a workgroup. He suggested that the Council could identify possible regulatory barriers in Maryland such as scope of practice and hospice requirements that are in Maryland regulations, and study the extent to which these requirements may create barriers to hospice care. Marian Grant responded that such a report has been done. Tricia Nay asked her for some examples of how Maryland regulations create barriers to hospice care. Marian Grant said that some states don’t allow hospices to care patients that have more than a 6-month prognosis and that some states don’t allow hospices to provide hands-on nursing care, which care has to instead be provided by home health agencies. Tricia Nay stated she was not sure those barriers exist in Maryland. Marian Grant said she would send the report to her.

Jack Schwartz suggested that the Council could study what an optimal regulatory environment would be to foster palliative care in Maryland. Marian Grant responded that certain CEUs on palliative care could possibly be required for recertification as some states do. Jack Schwartz noted that the role of the Council could be to help figure that out.

Anita Tarzian talked about the overlap between end of life issues and the work of ethics committees, that is, patient care advisory committees. She said that families should be educated about the dying process so that there is not undue suffering due to a lack of understanding about what happens when a feeding tube is withdrawn, such as the misunderstanding that the patient is being starved rather than putting in motion the natural dying process resulting from dehydration.

Marian Grant stated that MOLST form penetration should be studied. Anita Tarzian responded that health care providers are filling out the first page of the MOLST form. Tricia Nay noted that there is no legal requirement to fill out page 2 of the MOLST form.

Marian Grant asked how to get more people to fill out page 2 of the MOLST form. Alan Eason said that he is a certified master MOLST trainer but that he has a hard time getting entities to invite him to speak. He said that education is part of the issue, but not the whole thing. Christopher Kearney said that MOLST made a huge difference in documenting the conversation. Marian Grant said practitioners are not going to have time to engage in 30-minute conversations when they are only billing for a 6-minute conversation. Christopher Kearney noted that page 2 may be completed more often if there were financial incentives such as connecting a hospitalist's compensation to its completion.

Tiffany Callender informed the Council about a free Horizon Foundation webinar series on integrating advance care planning into health care settings. She will share information about the series with Paul Ballard to share with the Council.

Alan Eason expressed comfort with the Council endorsing the work of the Coalition. Marian Grant said the Council would be listed as one of the organizations that is supportive of the Coalition. Paul Ballard asked if the Coalition had a mission statement to see whether it was something the Council could endorse. Alan Eason asked if the Coalition could send its mission statement to Paul Ballard to share with the Council for its consideration and vote. Marian Grant said she would send the Coalition's mission statement to Paul Ballard.

Alan Eason asked if people knew of anyone who might like to serve on the Council as a physician with experience managing long term care.

Alan Eason shared a Daily Record Article dated January 25, 2019, describing former Council Chair Ted Meyerson's efforts on behalf of the American Association of Retired Persons to encourage the completion of advance directives.

There being no further business, the meeting was adjourned.