

State Advisory Council on Quality Care at the End of Life

Minutes from the September 10, 2021 Meeting

Meeting time and place: September 10, 2021, 10:00 a.m., via video conference call.

Council members present: Alan Eason; Paul Ballard (Attorney General's designee); Jane Markley; Rabbi Steve Glazer; Tricia Nay (Maryland Department of Health's designee); Susan Lyons; Karen Smith; Elena Sallitto; Senator Ben Kramer; Sister Lawrence Mary Pocock; Geoff Coleman; Carol Eckerl.

Others present: Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Patricia Alt; Stacy Howes; Molly Sheahan; Gail Mansell; Peggy Funk; Lakshmi Vaidynathan; Rachel Purnell.

Chairman Alan Eason opened the meeting.

Senator Kramer updated the Council regarding Senate Bill 837 he had sponsored that contained provisions designed to increase the number of advance directives completed in Maryland. SB 837 passed in the Senate, then stalled in the House Health and Government Operations Committee, which committee submitted the bill to the Health Care Commission for summer study by a workgroup. He said the workgroup already met once and was scheduled to meet again soon.

Senator Kramer noted that SB 837 was intended to implement recommendations made by the Council in its report to the General Assembly. The General Assembly had asked the Council to make recommendations regarding how to increase the completion of electronic advance directives. Senator Kramer said that in the next legislative session Delegate Bonnie Cullison will sponsor the bill in the House. She is the Chair of the subcommittee where the bill will be considered. Senator Kramer hoped they can come to a resolution with the insurance companies that had opposed SB 837 so that the bill can pass in the 2022 legislative session. If necessary, the bill may be able to be passed despite the opposition of the insurance companies.

Senator Kramer said that the ultimate goals of the legislation are to facilitate the use of advance directives, make it easier for all people to know about advance directives and to learn of their existence, and to facilitate getting them uploaded to a location easily accessible by everybody who needs to see an advance directive in a crisis in order to ascertain the patient's desires regarding their health care.

Alan Eason asked Senator Kramer to discuss the nature of the points raised by the opponents to the bill. Senator Kramer responded they do not want a mandate to provide information to their customers about advance directives. The goal is to convince the insurance companies to be active participants in helping to increase awareness of advance directives. Senator Kramer further noted that there is likely to be federal legislation in the not too distant future and this may be an incentive for insurance companies to already be participants in helping their customers when that occurs. He also said that hospitals were opposed because they would also be required to provide information to patients about advance directives. But he noted it would be the caregivers rather than the hospitals that would actually be providing the

information and that the hospitals would only be asked to facilitate the process. Indeed, he said that the caregivers at hospitals were very supportive of the bill.

Senator Kramer said that the opponents also made the incorrect assertion that under the bill there would be only one acceptable advance directive form, which wasn't going to work because there are so many different types of advance directives. However, he said the legislation does not require the use of any particular advance directive form and that any of the myriad available advance directives could be utilized, not just the electronic advance directive form made available by MyDirectives.com. He said while it is correct that MyDirectives.com is the only approved repository in the State approved to connect to CRISP (the State-designated health information exchange), MyDirectives.com makes available to CRISP all the various types of advance directive forms it receives, not just the advance directive form it makes available to its users. He said the confusion created by this misrepresentation made some legislators in the House anxious about supporting the bill because they did not get a chance to learn this was a misrepresentation. The bottom line is that the opponents do want to be bothered with taking on this function of sharing information about advance directives with their customers or patients. He said that if the bill has to be pushed through without the opponents' support, he and the bill's proponents will do that.

Gail Mansell said that her understanding was that The Joint Commission requires hospitals to provide information on advance directives for every patient who is admitted. So, if a hospital is pushing back, they probably shouldn't. Susan Lyons said her hospital has been complying with this requirement since 1991.

Jeff Zucker thanked Senator Kramer and Delegate Cullison for wanting to be part of this process. He said that in his 16 years of working on this issue he had never seen a group as diverse, focused, and determined as the Council members and their partners. He said the eyes of the United States and the world are watching what Maryland is doing to make citizens confident in having a voice heard in their own health care. He said that the good news is that the Council is made up of the right stakeholders and that the legislature asked for a thoughtful process that culminated in the report that the Council provided to the legislature. He said the Council's report was quite comprehensive.

Jeff Zucker said the legislation was quite simple but it was misunderstood. Because the bill's opponents did have to explain in their testimony the basis for their objection, the Council has a roadmap to solving this problem because the opposition showed what it is they are opposing. He said that by the bill's supporters correcting their opponents' misunderstanding, the payors will ultimately agree to the bill. He said a mandate would be created that when a person enrolls or reenrolls in insurance or gets their driver's license, that they would be given a chance to name a health care agent and to identify where they have placed your treatment goals, and that their goals would be accessible through their taxpayer-funded health information exchange, and therefore would normalize the advance care planning process. By doing so, he said Maryland has the chance to lead the world on solving this issue that Covid has shown us is so critical.

Jeff Zucker responded to Gail Mansell's question about The Joint Commission requiring hospitals to provide information on advance directives for every patient who is admitted. He said there has been very little enforcement of this existing requirement. Instead, he said that often the hospital provides the patient a digital admission form that includes a check box regarding whether they have an advance directive. And he noted that admission is a stressful time which does not lend itself to having a thoughtful conversation about these issues or to help the patient to remember that the patient already may have an advance directive. Rather, this is the way the hospital perfunctorily complies with the requirement that a patient be asked whether they have an advance directive and be offered a chance to discuss it with someone if the patient desires. These discussions almost never happen because the patient is not in the frame of mind to realize what it is being asked.

Jane Markley added that this requirement is usually carried out by an administrative support person who would not be capable of having an advance care planning conversation with the patient. Jeff Zucker agreed, saying that a registration clerk is trying to rush the patient through the admission process and is not trained in having advance care planning conversations. He said that policy makers have not changed the culture so that health care providers and patients can have a thoughtful conversation about these issues. Payors have an incredible opportunity in their work flow to talk to people before they become a patient at a much better time to consider these issues rather than in the middle of a crisis. He said that Maryland has a chance to do something very heroic in this legislative cycle.

Gail Mansell said that in contrast to what Jeff Zucker described, her hospital takes these issues very seriously. She visits every inpatient, has a conversation with them, and she would like to see every other hospital do the same because advance directives are very important documents. Alan Eason said this can start with a very basic conversation exploring some of the possibilities and concerns that are addressed by having conversations with family members. Gail Mansell said she has made certain that all of their physicians' offices have advance directives and MOLST forms, and that their administrative staff and registrars are all trained regarding them so that their health care system in addition to the hospital is aware of the need for them.

Jan Markley asked Senator Kramer how Council members could best help in contacting legislators. Senator Kramer said that every Council member has three State delegates and a senator that could be contacted and in particular those Council members represented by legislators who sit on committees with jurisdiction over the issue should be contacted. Senate Bill 837 will have a new bill number in the next session. The bill will likely contain some changes as a result of the workgroup's work over the interim. Once a new bill is introduced, Council members could reach out to legislators regarding the importance of the bill to their fields in which they practice and describe the value it creates for the residents of Maryland. Even for those legislators that don't represent individual Council members, it is valuable for Council members to reach out to legislators on committees that will hold hearings on the bill.

Alan Eason said he appreciated the work that Senator Kramer is putting into this legislation and that at a later meeting the Council will further consider how it can support this legislation more specifically and concretely. He said he was surprised at how much of an uphill

battle it was to try to get SB 837 passed when it seemed so simple to support it. Senator Kramer agreed it shouldn't be this difficult but said his experience has shown that even the most common-sense legislation can be a battle. He noted it took him years to get common-sense ignition interlock legislation passed with regard to drunk driving and which legislation very successfully changed the behavior of people who would routinely drink and drive. He expressed his confidence that this legislation would succeed too. Dan Morhaim said to focus on the Speaker of the House and the Chair of the Health and Government Operations Committee.

Elena Sallitto thanked Senator Kramer for sponsoring the bill and said she and her colleagues at the Elder Law Section of the Maryland State Bar Association would be happy to help with this important legislation. Jeff Zucker noted that the American Bar Association's elder law unit has issued a document about the 10 myths of advance care planning and advance directives and has reissued it every 2 or 3 years because people have been given misinformation. He said this document helps to dispel some of the confusion that lawyers perpetuate without meaning to about what document is allowed, how it needs to be signed, where it needs to be stored, and how it should be updated. The fact that the ABA keeps having to reissue this document shows that the confusion insurers and others have regarding this issue is systemic. He said emergency room doctors should be able to get from CRISP information regarding the patient's goals of care and who speaks for the patient when the patient is received from EMS. He said it really shouldn't be this hard. He first wants the 1.4 million advance directives that have already been completed to get into the electronic medical record and to be accessible in CRISP. By doing this, there will be momentum to get the rest of Marylanders to prepare advance care plans and make them accessible to health care providers.

Alan Eason agreed that increasing the accessibility to advance directives is important and noted he has seen at hospital ethics committee meetings very long advance directives prepared by attorneys. This is the case despite the fact that Maryland makes available a more concise advance directive on the Attorney General's website and that people can prepare a simpler advance directive that is available online. These long and complicated advance directives make it difficult for a hospital to ascertain basic information such as the identity of the health care agent.

Jane Markley followed up on the issue discussed by the Council at its last meeting regarding prisoners being denied visits from a chaplain at the end of life. Jack Schwartz said the case he mentioned at the previous Council meeting is being written up as a case study to be published in the Maryland Healthcare Ethics Committee Network (MHECN) newsletter, which is produced by Diane Hoffman out of the University of Maryland School of Law. The case study will be accompanied by a couple of commentaries about it that will also be published in the newsletter. Thus, he said it would make sense to wait for the publication and that the Council will be able to discuss the issue at its next meeting regarding what the Council might want to do. Rabbi Steve Glazer noted there is also a current case of a prisoner scheduled for execution in Texas who was denied access to his personal minister. Jack Schwartz said it is a crucially important issue where the role of clergy and spiritual care is so important for virtually anyone nearing the end of life and that prisoners are no exception to this need. He suspected there is

considerable variation among jurisdictions and that the Council is wise to consider this issue by starting with a concrete case such as the one that will be written about in the MHECN newsletter.

There being no further business, Alan Eason adjourned the meeting.