

State Advisory Council on Quality Care at the End of Life

Minutes from the May 14, 2021 Meeting

Meeting time and place: May 14, 2021, 10:00 a.m., via video conference call.

Council members present: Alan Eason; Paul Ballard (Attorney General's designee); Tiffany Callender Erbeling; Jane Markley; Christopher Kearney; Donald D'Aquila; Rabbi Steve Glazer; Shahid Aziz; Tricia Nay (Maryland Department of Health's designee); Susan Lyons; Yvette Oquendo Berruz; Sara Hufstader; Karen Smith; Elena Sallitto; Hank Willner; Stevanne Ellis (Department of Aging's designee); Senator Ben Kramer.

Others present: Jack Schwartz; Ted Meyerson; Dan Morhaim; Elizabeth Clayborne; Jeff Zucker; Patricia Alt; Howard Sollins; Harold Bob; Stacy Howes; Molly Sheahan.

Chairman Alan Eason opened the meeting and Paul Ballard asked people to email to him any corrections to the draft Council minutes from the February meeting.

Paul Ballard discussed certain bills of interest to the Council that were introduced during the 2021 session of the General Assembly. He said that House Bill 1261 was passed, which bill concerned the electronic execution of wills, powers of attorney, and advance directives. With regard to advance directives, he noted that the bill permanently recognized the validity of all advance directives prepared through the remote electronic process authorized by the Governor by executive order during the pandemic. House Bill 1261 also authorized the electronic presence of a witness to the execution of an advance directive when the electronic presence of the witness is comparable to being in the physical presence of the declarant signing the advance directive. While it is not clear how this will work in practice, the bill does authorize an additional method of witnessing an advance directive.

Paul Ballard also discussed House Bill 203 which in addition to other provisions regarding wills, would have required all advance directives to be notarized. The Council, through Chairman Alan Eason, expressed its serious concerns about the bill to the sponsor because such a requirement would deter people from completing advance directives. The sponsor promised to delete this provision from the bill. The bill did not make it out of the House committee. Paul Ballard also mentioned House Bill 983, which passed as an emergency bill and requires the Maryland Department of Health to write visitation guidelines applicable to nursing home to be used during catastrophic health emergencies.

Dan Morhaim spoke about Senate Bill 837. He thanked Senator Ben Kramer for all his work regarding this bill which passed the Senate overwhelmingly thanks to his efforts. The bill did not make it out of the House Health and Government Operations Committee. Dan Morhaim believed that one of the problems was the lack of a Delegate on the Council, which vacancy has remained since he retired from the House. He said that it is important to fill that seat so that a Delegate can partner with Senator Kramer on these issues and suggested that Chairman Alan Eason write a letter requesting that a Delegate be appointed to the Council. He said that the Maryland Hospital Association and the insurers' groups opposed the bill, incorrectly claiming

that the bill would require people to use one kind of advance directive in their electronic systems. The Committee Chair did not want to sort out the issues raised by them.

Senator Kramer thanked former Delegate Morhaim for all his hard work on the bill and for his compelling testimony. He also thanked Elizabeth Claiborne for her compelling testimony. He said they got the bill through with overwhelming support in the Senate despite the false rhetoric put forth by the Maryland Hospital Association and insurers. He said that the bills would have created nominal requirements for hospitals and insurers. In the Senate Finance Committee, he was able to counter their objections as being baseless and motivated by their selfish interests not to be bothered with being required to help expand opportunities for Marylanders to complete advance directives. He said it hurt not having a Council representative from the House who could explain this to the House committee, and thus the complaints made by the hospitals and insurers resonated more broadly before the House committee without anyone there to refute them. He said he did not know how the bill will succeed without a Delegate's assistance.

Senator Kramer said that the bill was sent to summer study to look to find some happy middle ground. But he doubted that the hospitals and insurers will simply agree to take on the responsibility of encouraging patients and the insured to complete advance directives as envisioned in Senate Bill 837, and that is difficult to see how the opportunities for advance directive completion can be further expanded without their assistance. He expressed hope that the bill could be passed in the 2022 legislative session. Hopefully, the Council will work on promoting the bill in the interim. Senate Bill 837 was prepared late in 2020 right before the 2021 session began and they didn't have time to market it in advance to legislators that would be involved in the decision-making process. He believed that the bill may ultimately go to Delegate Bonnie Cullison's subcommittee and that the Council can start to work with her and be better prepared going into the next legislative session.

Dan Morhaim said that the groups supporting the legislation were ones representing people such as the Horizon Foundation and AARP and those in opposition were institutional organizations who represented their self-interest as much as the general public, which was disappointing. He asked people on the Council to go to their own institutions, saying that he would approach the hospital system where he works and ask the hospital to request that the Maryland Hospital Association change its position.

Hank Willner asked for clarification as to what the objections were. Senator Kramer responded that the Hospital Association and insurers objected to the bill's requirement that the patient be informed of the opportunity to prepare an electronic advance directive. Dan Morhaim said physicians would have to do it and hospitals did not want to be told what to do. He said it is worth reading the testimony of the hospitals and insurers because some of the testimony is incorrect, for example, including an incorrect statement that the bill would require a patient to use a particular kind of advance directive. He said they did not get much help from the Health Care Commission because they said electronic advance directives are not being used. But Dan Morhaim said that increasing the use of electronic advance directives was the point of SB 837. Hank Willner said that was very sad.

Alan Eason asked Tiffany Callender Erbeling to talk about the plan for passing the bill in the 2022 session. She said that the Horizon Foundation's Speak(easy) Howard has been a great campaign for people to create advance care plans but is still trying to tap into that large group that have not engaged in advance care planning. For the next year, they are putting their energy into supporting Senator Kramer and Dan Morhaim in their legislative efforts regarding Senate Bill 837 in 2022. MedChi will lead a coalition in support of this legislation in 2022, in partnership with the Horizon Foundation and AARP to have conversations with MHA and the health systems so that in 2022 legislation can be passed. This coalition is called the Honoring Choices Coalition and includes MHA among other organizations (www.medchi.org/Maryland-Honoring-Choices-Coalition). Their mission goal is that every Maryland resident is presented with the opportunity to complete an advance care plan. She invited Council members to join the coalition and to encourage other people to join. There will be a policy and advocacy coordinator for the coalition. Alan Eason liked the wide reach of the coalition that Tiffany Callender Erbeling described and said it made him very hopeful for the coalition's success with the legislation.

Jeff Zucker said there are already over a million people that have completed advance directives who don't have confidence that their voices will be heard in Maryland's health care system. These people's advance directives can be connected to CRISP but are not being uploaded onto CRISP because they don't know how, are not aware that they can, and they don't have confidence that the doctor is going to push the button to access it, then read and honor it. If they were made aware of this and given confidence that the health care system would read and honor their advance directives uploaded to CRISP, they would do so and it would then be easier to convince the rest of Marylanders to complete advance directives and upload them onto CRISP. This is because they are going to know people from that group of 1.2 million people that already did it. This can be accomplished through quality measures such as requirements for the hospitals to report what percentage of their patients have engaged in advance care planning, rewards for doctors who are finding and using patients' advance care plans, and education to doctors that it is worth clicking the link to advance directives. He thanked the advocates for SB 837 and hoped that the legislation could pass in the 2022 legislative session.

Jack Schwartz said that a physician at Frederick Memorial Hospital had recently posted a message on the Maryland Healthcare Ethics Committee Network (MHECN) listserv that read: "I have a question for the group. Our Chaplains are denied visits with inmates in our hospital. It's a law enforcement decision, not a hospital decision. I'm wondering if this is just our local law enforcement or across Maryland. Recently had a patient /inmate die on hospice care here and the Chaplain was denied a visit. Personally, I feel this is an ethical issue and so does the Chaplain." Jack noted that it was a very brief account and there were a lot of facts not presented such as who made the decision, was it a correctional officer at the bedside, was it the warden, and what was the context here. So, the first thing that is needed is more facts. So, Diane Hoffman from the University of Maryland School of Law, who is the leader of the MHECN, is asking for the chaplain or the physician to write this up as a case that would be published in the MHECN newsletter, with commentary from an ethicist and somebody from the State Department of Public Safety and Correctional Services. So, there will be more to be learned about this particular case.

But taking this at face value from what we know, it struck him and others in the MHECN as just a shocking denial of a critical element of quality care at the end of life to deny someone spiritual support from a chaplain as he was dying. The case might also open up beyond the specifics of chaplaincy visits a set of broader issue about the situation of inmates nearing the end of life. Whose involved in goals of care decisions? Are family members who in other circumstances would be surrogates permitted to act as surrogates if the patient lacks capacity? Are hospice and palliative care services genuinely available to inmate/prisoner patients nearing the end of life? So, at this point he is just bringing to the Council's attention that this issue has come up regarding the specific issue of chaplaincy visits for prisoners nearing the end of life. It is possible that the scope of inquiry might later be broadened regarding whether our society in Maryland is acting decently with regard to prisoners who are nearing the end of life. He will keep the Council updated on what MHECN learns

Howard Sollins asked if there is a logical advocacy organization for incarcerated individuals and their families that would want to be part of the conversation. He said that from time to time he has interacted with people with disabilities who have been arrested and held in detention. He said that each separate jurisdiction has its own penal system. Some facilities are accessible for individuals with disabilities and some are not. There is not one comprehensive medical system for the criminal justice system in Maryland. Access to care can be markedly different between larger urban jurisdictions and smaller rural counties with older criminal justice infrastructure. So, we can't assume that a good idea would be adopted all at once across Maryland.

Susan Lyons said that they have a large prison complex near her hospital in Hagerstown. She said their palliative care chaplains make routine visits with State inmates who are inpatients at the hospital or who come to the hospital's cancer center who are coming in for their cancer treatments. They work through the warden to get family presence for folks who are not expected to survive so that they can come in and be with their loved ones. She said they have not had issues with the warden regarding this and the hospital has advocated for inmates to get compassionate medical parole if they are not likely to survive for more than a few days. The biggest obstacle they face is getting transportation for the family because the inmates' families come from all over Maryland and a lot of them don't drive. So, the hospital will find them rides so that they can be with their loved ones when they are dying.

Jack Schwartz said what seems to be the case is a patchwork of various practices and that decisions ought not to be made at the bedside by an individual correctional officer and ought not be made because one or another warden of a State correctional facility or one or another county sheriff from a local detention center happens to be more humane. Every dying person in Maryland ought to have quality care at the end of life and that includes prisoners. This should not be at the whim or discretion of particular State or local officials. Instead, there needs to be a State-wide policy developed on this issue and that is where the Council can play a role.

Rabbi Steve Glazer assumed that we don't know the specific details of the case that was discussed but that going forward they may become available. Jack Schwartz confirmed that was correct and said that Diane Hoffman is soliciting feedback to establish important details such as

whether the prisoner was in State or local custody and what was the sequence of events. These results will be written up regarding the particular case and then people can react. The particular facts may shed light on some of the broader issues.

Alan Eason said he liked the idea of gathering information on the case, and that as the Council pieces together the facts the Council could potentially advocate for legislation that might address the issue. In the meantime, the Council could reach out to the Commissioner of Corrections and individual jurisdictions. Based on his prior work experience as an Assistant Attorney General working in this area of law, he agrees that it is accurate to say that the policy will vary depending on the local person on site.

Dan Morhaim asked if the Council agreed to take policy steps regarding the issue. Alan said that as the Council gets more information, the Council can then determine the best way to get involved and do something.

Hank Willner asked about the status of the Medical Aid in Dying legislation. Alan Eason said he stopped working with Compassion and Choices when he became Chair of the Council so he does not know what their plans are for the legislation. He suggested that information could be found at the Compassion and Choices website. Dan Morhaim said that a bill was not introduced. Jack Schwartz noted that the lack of a bill shows that there was at least a decision to postpone a concerted effort in Maryland. Hank Willner said that in his work he had been getting increased requests for that option.

Shahid Aziz said it is a recurring frustration for him that numerous educational training sessions do not result in the completion of advance directives. He said that now when he gives talks he tells the participants that at the end of the talk there will be a working document for them to complete and sign at that time. He would like to see the completion of advance directives at the end of talks. He is also focused on getting health care providers to complete their own advance directives, which would make it easier for them to convince others to complete them. He said it was amazing how many health care leaders have not completed their own advance directives. Tiffany Callender Erbeling said in Chat: "I've also found it powerful to frame failing to honor wishes as a preventable harm. Health care systems must do all they can to prevent harms like surgical site infections and bloodstream infections... they should also do everything they can to honor EOL wishes."

Hank Willner echoed Shahid Aziz's frustrations and said he now gives talks with piles of 5 Wishes advance directive forms. Jack Schwartz said that Paul Ballard circulated for people's information a National Academies' summary of a workshop late last year on advance care planning. Although this is not the typical Academy's report with a set of recommendations, it does capture individual experts and members of the community talking about their experience with advance care planning, what works and what doesn't. So, Jack Schwartz said that potentially this is a recent document that may give Shahid Aziz some thoughts or ideas. One thing in Jack Schwartz's reading that emerges is that while attention to advance care planning captured ultimately in an advance directive document is crucially important, there also needs to be a parallel track to try to address improved care for patients who didn't do advance care

planning and whose family members need help to improve their decision making in a moment of crisis.

Howard Sollins said that perhaps clinicians and academics may be in an echo chamber regarding this issue and should also explore alternative ways of promoting advance care planning. He cited the example of a program at the Maryland Institute College of Art on design thinking that helped his nonprofit organization market services to senior village. He said it was very creative work by students. He wondered whether it would be helpful to sit down with someone outside the medical world of end of life care who is in the business of popularizing things. Alan Eason said he liked that idea a lot. He said he has done advance directive training for both community members and health care professionals after being trained by the Maryland Office of Health Care Quality and because of the pandemic and other things he has not been able to do it for a long time. He asked Howard Sollins and others to email him about different possibilities of reaching out to people in different ways. He said that the PowerPoint presentation he uses emphasizes the importance of having a discussion with your health care agents in addition to the completing an advance directive because the health care agents need to know as much as possible about what would you want if you were facing an end of life situation. Hank Willner asked Alan Eason to send him the PowerPoint to look at and Alan Eason agreed and asked him to send him a reminder to do that.

Jane Markley said she was happy to participate in that dialogue. She is participating in an artistic community in Montgomery County. She said her goal has been to get out of the health care side of the house and go to the other genres of activity that are out in our community and try to get them talking about advance care planning. She said she would soon be teaching again at OASIS and she has that community being her marketeers for that program. She said she would like to see more of that go on.

Howard Sollins said he would reach out to Paul Ballard and he could coordinate how the Council wants to do this. He said trying to convince people who don't want to confront their own mortality is less successful than going to adult children who are going to be faced with picking up the pieces if their parents don't engage in advance care planning. He said he advises young attorneys in his law firm who are having a baby to do 3 things: (1) get your child a social security number, 2) have a will with a guardianship for your children, and (3) have an advance directive so that your family doesn't have to figure it out. He said that the pandemic has accelerated the retirement of baby boomers and made people think about these issues, presenting an opportunity to accelerate the conversation about advance care planning.

Dan Morhaim said that when he was in the legislature he always kept a stash of advance directives in his office for people to complete when they came to his office to lobby him about anything relating to healthcare. He said that he and Patricia Alt who was on the meeting call are both active American Public Health Association members. The APHA on their website has 33 topics they discuss on their website but do not have a single word about aging, dementia, or advance care planning, hospice, or palliative care. Surprisingly, they are even having a hard time convincing the APHA that any of these issues should be discussed on their website as a public health issue.

Jeff Zucker noted that he has retired from ADVault. He is still very dedicated to making sure people get their voice heard and the two people he was closest to that passed away and whose experience resulted in him starting the company 14 years ago had lived in Maryland. For that reason, he is vested in making sure Maryland gets this right. There has been a lot of money spent on that sort of outside the box thinking. He said that it was good to get away from the mindset that advance care planning is somehow about dying and not about living. The COVID experience has pushed people away from the life that used to be and has made them more comfortable with technology. So, some of those promotional efforts probably should be updated and he said Howard Sollins' point is well taken. But he wanted to remind everyone that the easier task is to get the 1.2 million people who have already completed an advance directive to upload it into CRISP. By doing so, they will then sort of spur that grass roots crowdsourcing movement that causes everyone to say "Oh, I did it, why didn't you do it too?" or "I didn't realize it was that easy, I can do it." And people trust their neighbors and their families and their friends more than they will ever trust a public service announcement. And it is also important that their doctor actually used CRISP. There should be a poll given to doctors asking how many of them found advance care plans during COVID, and how many of them wished they could have found advance care plans during COVID and that would have helped them do a better job. And then a statement could be issued to local media that says that 80 % of the doctors who engaged in the poll couldn't find the voice of the patient, didn't know who to speak to, and couldn't do their job as well. Uploading the 1.2 million advance directives onto CRISP will help doctors do their jobs better. Such a poll issued by the Council, MedChi, the Maryland Hospital Association, etc. would help Senator Kramer's efforts to get legislation through the House of Delegates.

Hank Willner asked whether an advance directive on MyDirectives.com is automatically uploaded to CRISP. Jeff Zucker said it is automatically in CRISP but unfortunately it is only in CRISP if you used a Maryland address for your residence. So, people who also live in other States do not have their directives automatically in CRISP. He said that the Maryland Health Care Commission should fix this problem.

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