

State Advisory Council on Quality Care at the End of Life

Minutes from the February 11, 2021 Meeting

Meeting time and place: February 11, 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; Sister Lawrence Mary Pocock; Carol Eckerl; Yvette Oquendo Berruz; Sara Hufstader; Karen Smith; Geoff Coleman; Elena Sallitto.

Others present: Marian Grant; Jack Schwartz; Ted Meyerson; Dan Morhaim; Elizabeth Clayborne; Jeff Zucker; Patricia Alt; Rebecca LeFleur; Harold Bob; Peggy Funk; Kathryn Walker; Rachel Brandon; Sonja Chestnut; Carolina Ramirez; Julie Deppe; Karren Pope-Onwukwe; Gail Mansell.

Chairman Alan Eason opened the meeting with some brief comments and asked Paul Ballard to discuss the Council's report to the legislature regarding electronic advance directives.

Paul Ballard summarized the Council's report. The General Assembly had asked the Council to study and make recommendations regarding how to increase the use of electronic advance directives and to issue a report by December 1, 2020. The Council then formed a workgroup and Tiffany Callender very effectively led the workgroup whose members included Niel Rosen, Peggy Funk of the Hospice and Palliative Care Network, Jeff Zucker of ADVault, Nathaniel Cohen of MedChi, and Paul Ballard. The workgroup studied what the existing mechanisms are that enable people to complete advance directives and what possible methods might be used to increase the use of advance directives.

Dan Morhaim said that workgroup wrote a very extensive and compelling report that shows how to address the issue. He and Senator Kramer turned the recommendations of the Council's report into Senate Bill 837. What the bill primarily does is to require insurance carriers to take some responsibility in encouraging their policy holders to complete advance directives. Insurance companies have been reluctant to do this because it might make them wrongly appear as if they are encouraging the completion of advance directives to avoid paying for treatments. Requiring them to encourage the completion of advance directives can help to prevent this misperception. The bill would require insurance companies to send people periodic notices to encourage them to complete electronic advance directives through vendors approved by the Maryland Health Care Commission and that meet their technology, security, and privacy standards, which at the present time is ADVault (MyDirectives.com). Five Wishes or any other version of an advance directive can be uploaded into this electronic system. He recommended that the Council write a letter in support of the bill and that others support the bill. He said that MedChi is very likely to support the bill and they had helped staff this effort.

Alan Eason proposed that the Council write a letter of support for Senate Bill 837.

Tiffany Callender complimented Dan Morhaim on the speed at which he was implementing the recommendations in the Council's report. She noted that Senate Bill 837 requires that the Maryland Health Care Commission, the Maryland Department of Health, and carriers take certain actions but that when she had spoken with representatives of the Maryland Health Care Commission, they did not know about the bill. She asked Dan Morhaim whether there were conversations with the Commission, the Maryland Department of Health, or insurance carriers about the bill. Dan Morhaim responded that those conversations are all getting underway. Because of the quick timeline in getting the bill introduced, he had to first make certain the bill's language worked. Dan Morhaim responded that he and MedChi, including Elizabeth Clayborne, will be working on promoting the bill.

There was a consensus among the Council members that the Council members send a letter in support of Senate Bill 837. Dan Morhaim volunteered to work on the letter with Paul Ballard and the workgroup.

Dan Morhaim mentioned House Bill 203 which would require a will and an advance directive to both be notarized. Alan Eason said he wrote a letter to the sponsor, Delegate Jackson, and someone in his office responded he was planning to amend the bill to take out this requirement for a notary. Paul Ballard also learned that Senator Klausmeier intended to make the same amendment to the cross-filed bill, Senate Bill 519. Peggy Funk said she understood that this requirement was taken out of the bills. Dan Morhaim said that the bills as originally introduced would create a barrier to people in their efforts to complete an advance directive. Sonja Chestnut and Marian Grant agreed.

Paul Ballard discussed House Bill 1261 and Senate Bill 820, which cross-filed bills concern the execution of wills, powers of attorney, and advance directives. The bills would: (1) permanently validate advance directives executed in accordance with the Governor's executive order issued during the catastrophic health emergency declared by the Governor because of the COVID-19 pandemic, which executive order authorized remote witnessing and electronic signatures; and (2) validate an advance directive that is signed and witnessed in the electronic presence of the declarant. He said that the bills would not impact the existing law that allows an electronic advance directive to be unwitnessed if it meets the National Institute of Standards and Technology requirements. Dan Morhaim asked the attorneys at the meeting to look at the bills again and verify that this is correct.

Jeff Zucker said the witness and the notary is the old-fashioned way of verifying that the expression of the goals of care in an advance care plan really come from the patient. In the modern world the health care practitioner can look at a video message instead. CRISP can accept a secure video message that expresses the treatment wishes of the patient. People are creating video messages today that don't get witnessed and don't get notarized. What the health care practitioner really needs to know is who speaks for this person, their goals of care, and whether the expression of the person's treatment wishes really came from that person. So, the digital world allows for an expression of wishes that wouldn't conform to the old-fashioned way of witnessing and notarization. ADVault supports the Council's report and Senate Bill 837 because it pushes for the modernization of advance care planning.

Alan Eason introduced Sara Hufstader as a new Council member and asked her to describe her background. She is the lead coordinator for the Voice Your Choice Program that is operated by the Jewish Social Service Agency (JSSA) and funded by the Nexus Montgomery Regional Partnership. The Voice Your Choice Program is a community-based organization that trains and educates health care providers and community members about advance care planning. The program reaches out to everyone in their community, which includes Montgomery County and Prince George's County, regardless of where they provide, or receive, health care. Before that, she worked with at the Center to Advance Palliative Care (CAP-C) with Marian Grant. At CAP-C, she worked on a project called the Hub which was a project to examine different ways in which people who are seriously ill can obtain quality care as the health care system transitions from a fee-for-service system to a value-based system. She had earlier worked with Marian Grant at the Pew Charitable Trust as the project officer for a project for improving care for individuals near the end of life. She also spent many years working for a nonprofit organization called Sanctuary for the Dying that worked to ensure that vulnerable populations had access to serious illness care and end of life care. Her passion for advance care planning and caring for people who are seriously ill originated with her personal experiences being the primary caregiver for a seriously ill loved one as a young adult.

Jack Schwartz gave a brief update on the Allocation of Scarce Resources issue. He said this is an exercise in contingency planning regarding what Maryland hospitals would do if faced with a situation in which there is overwhelming demand in excess of supply for ventilators, ICU beds, or other resources. Under those circumstances there has to be rationing and the question is how do you ration, badly or better. Better rationing is clinically sound, ethically grounded, free of bias, and feasibly to be done under intense time constraints. Considering what happened in New York and Los Angeles, it was well that five Maryland health care systems, Johns Hopkins, Maryland, MedStar, LifeBridge, Luminis, and the clinicians at those systems began a collaborative process to try to develop guidelines for the allocation of scarce resources. Because the Governor has authority to order rationing if need be in a catastrophic health emergency, the five systems shared their drafts with the Governor's office as they developed the guidelines. The one element that was missing from that process was transparency. Because the more eyes there on guidelines like this, the better they're likely to be. So, the Council wrote a letter to the Governor requesting that the current version of the five systems' guidelines be posted on a State website so that the widest range of people could see the guidelines.

Jack Schwartz's understanding is that the Governor's office has not replied to the Council's request and as far as he knows the guidelines are not posted on any State website. Instead, those involved in the five hospital systems developing the guidelines wrote a paper about their process, which paper has been accepted by the journal CHEST. A pre-publication of the version of the guidelines is on the CHEST website. The website includes a supplement which captures the late June, 2020 version of the guidelines which is now on the journal website.

Thus, in effect these draft guidelines have entered the public domain in this indirect manner. Of course, people other than clinicians don't generally look at medical journal websites. So, the Maryland Healthcare Ethics Committee Network has taken the guidelines document and

put it on the Network's website and has solicited comment about the document. They have circulated the guidelines to the Chairs of ethics committees in Maryland and to a listserv of ethicists. There had been about two dozen responses, including comments and suggestions from disability rights and aging rights advocates. The intention of the Network is to post the comments received regarding the guidelines so that people can see the comments. He will give Paul Ballard a link to the Network's webpage that he can share with the Council. He said that despite the recent decline in hospitalizations, the guidelines are still not an academic exercise because depending upon what happens with the COVID variants, we might be in this situation again where there may be a scarcity of resources. He invited people to take a look at the guidelines and to take a look at the comments. The Council may have more to say on this topic in the future. But at least through this workaround of publishing the guidelines in the journal CHEST and posting them on the Maryland Healthcare Committee Network's website, the guidelines are available to those who want to see them.

Harold Bob said that in March and April of 2020 he was on calls with the five health care systems that had formed collaboratives with the nursing home industry. Because of the communications between those teams, Maryland was able to avoid what happened in New York, New Jersey, and California, which was a total breakdown of the hospital systems. So, if the nursing homes knew that there were no ICU beds and there were no ER beds, in a couple of the nursing homes, the hospitals' "go teams" would come out and assist in the nursing home to take care of residents on a high clinical basis. He said this could happen again but the advantage now is that the nursing homes have probably vaccinated about 75% of the staff and 75% of the patients. He said there has been really great State leadership and really great hospital leadership. Jane Markley commented it was nice to hear from him that things had gone well from the State perspective.

Sara Hufstader gave a presentation on Voice Your Choice. She said they are updating their website and adding in a resources tab that is split between providers and the community. The community resources will be provided in different languages, including English, Spanish, French, Korean, Chinese, Vietnamese, and Russian. They are re-recording their webinars and breaking them down into mini-webinars. For providers, these webinars include online advance care planning, resources, reimbursement, and conversation supports. Advance care planning resources include Advance Care Plan versus MOLST, cultural considerations for conversations around advance care planning, how to find an advance care plan, an advance directive, and CRISP, reimbursement for advance care planning, tools for advance care planning, and conversations.

The website also has advance care planning FAQs for providers that will be accordion-style so that that user can click on the question and the answer will pop down rather than having to read through a PDF. On the community side, the mini-webinars will be anywhere from 3 to 7 minutes. Regarding the specialized webinars, they have partnered with the Archdiocese of Washington to do a webinar for individuals in the Catholic community. They have also partnered with Cornerstone Montgomery to do an advance care planning webinar for the mental health community which will be highlighting the mental health care advance directive.

Voice Your Choice is creating a webinar regarding advance care planning for individuals with early stage dementia. They are also working on an advance care planning webinar for first responders and health care workers. They also have some how-to guides on how to use the online platform which is MyDirectives.com, how to create an online advance care plan, and how to upload an existing advance care planning document. The how-to guides are very brief and streamlined. They also have resources for COVID, how to choose a health care agent, and what does it mean to be a health care agent, as well as 18 questions that are asked and answered in accordion-style. They are translating a number of these materials into the six languages she mentioned. They have a webinar on how to create an online advance care plan.

Voice Your Choice was just able to secure 200 copies of the Five Wishes advance directive in each of these six languages and will be able to share them on their website. They will then be able to upload the Five Wishes advance directive in one of these languages other than English onto the online platform. They will have a webinar for how to upload these directives onto the online program and the webinar and the guide will be available in these six languages. Each of their resources will be contained in these six languages. She said they are coming close to completing the work on these resources and that she will send out an email when these resources are available.

Voice Your Choice is a grant-funded program and has been funded for two years very generously by the regional partnership of the six participating hospitals and the four participating hospital systems. The funding continues until the end of February, 2021 for program year two. Voice Your Choice is searching for funds for program year three and at this point has not been able to find funding given the difficulties posed by the confluence of tight funding and COVID-19. Regardless, the website and platform will continue. ADVault has been very generous in allowing Voice Your Choice to be able to have the platform continue on for awhile and they are still negotiating regarding how long that will continue. Lexus Montgomery is going to continue to host the website on their server and have agreed to host the website in perpetuity at this point so that those resources will be available to both the community as well as to providers. This website can be found at www.voiceyourchoice.org.

Voice Your Choice is also creating a professional 90-second video about advance care planning in an animated style to reach people in an interesting way. The Conversation Project has played with a few things to make advance care planning a little more lighthearted but obviously still convey the message. This video should be completed by the end of March, 2021. Voice Your Choice has funds through the end of April, 2021. But both the website and the platform will continue to be available to both providers and the community.

Council members complimented Sara Hufstader on her work and on the Voice Your Choice website. Sara Hufstader thanked the Council members and told them she would let them know when additional resources are uploaded on the website.

Tiffany Callender said the Horizon Foundation provided a grant to MedChi to bring on a project manager to lead a short-term coalition to support and help implement the Council report's recommendations and Senator Kramer's subsequent Senate Bill 837 to increase advance care planning in the State of Maryland. If Senate Bill 837 should not pass for whatever reason, that

coalition will be gathering support among organizations and individual to implement the Council's recommendations and do the advance work needed to help such a bill get passed in the General Assembly's 2022 legislative session. She will be presenting an update about the coalition at the Council's next meeting.

Paul Ballard discussed Senate Bill 820 which provides for remote witnessing. He asked Council members if they wished to support the bill if he confirmed its only impact was to confirm the permanent legal validity of advance directives witnessed remotely through electronic means in accordance with the Governor's executive order issued during the COVID-19 pandemic. Ellen Sallitto said she was fine with Senate Bill 820 if it just preserves the integrity of advance directives executed remotely during the pandemic in accordance with Governor's executive order. She noted it is hard enough to get people to prepare advance directives without making them prepare them again after the Governor's executive order expires. Alan Eason suggested that Paul Ballard email the Council the results of his review and that the Council could then decide whether to take a position on the bill. Paul Ballard agreed to do that.

Jeff Zucker said that enactment of Senate Bill 837 would make Maryland significantly ahead of the other 49 states in the area of advance care planning. The key piece of that legislation is to help health insurance plans do the right thing for their beneficiaries because they will be able to explain to beneficiaries that the government is requiring them to encourage beneficiaries to engage in advance care planning. This is very consistent with what the Biden administration and the Center for Medicare and Medicaid Innovation wants to do regarding Value-Based Insurance Design (VBID), that is, requiring all Medicare Advantage organizations that are participating in VBID to do digital advance care planning. He added that legislators from three other states are looking at Senate Bill 837 as a model for their own legislation.

He also said that the COVID-19 vaccine work flow is an opportunity for providers to engage with a patient about their existing advance directive and have them take a picture of it with their phone and upload it to MyDirectives.com for free. MyDirectives.com will then feed the advance directive to CRISP in real time. If they don't have an advance directive, the provider can tell the patient to go to the Voice Your Choice or Speak(easy) Howard websites and prepare an advance directive, and then click the link at MyDirectives.com. There is thus an opportunity for people to get their advance directives prepared and uploaded into CRISP while they are getting vaccinated.

Alan Eason thanked everyone for their input and viewpoints. There being no more business, he adjourned the meeting.