

## State Advisory Council on Quality Care at the End of Life

### Minutes from the November 12, 2020 Meeting

Meeting time and place: November 12, 2020, 10:00 a.m., via video conference call.

Council members present: Alan Eason; Paul Ballard (Attorney General's designee); Tiffany Callender; Hank Willner; Marian Grant; Jane Markley; Stevanne Ellis (Maryland Department of Aging's designee); Senator Ben Kramer; Christopher Kearney; Donald D'Aquila; Rabbi Steve Glazer; Shahid Aziz; Christian Miele (Department of Disabilities' designee); Tricia Nay (Maryland Department of Health's designee); Susan Lyons.

Others present: Jack Schwartz; Sara Hufstader; Ted Meyerson; Dan Morhaim; Elizabeth Clayborne; Jeff Zucker; Carrie Durham; Niel Rosen; Stacy Howes; Patricia Alt; Lauren Cashion.

Chairman Alan Eason opened the meeting with some brief comments regarding the prior Council meeting, praising the quality of the discussion.

Paul Ballard discussed draft guidelines regarding the allocation of scarce critical care resources and a possible Council letter to Governor Hogan from Chair Alan Eason to support making the general public aware of these potential guidelines. He recounted how Jack Schwartz had presented to the Council regarding this issue in September. Paul Ballard thought that the Council may wish to discuss the option of presenting a letter to the Governor requesting that the potential guidelines be made available for public review and comment by posting these draft guidelines on the Maryland Department of Health's website. He said this would promote transparency and enable people to think about this issue and comment on the draft guidelines. He said it would be shocking for a patient to learn that a life-saving treatment may not be available and instead be given to another patient. Given the real possibility of this occurring in Maryland based on what was happening elsewhere in the country, he believed it may be important to educate the public about these potential guidelines that could be applied in such situations. He asked Jack Schwartz if there was any update since the September meeting.

Jack Schwartz said the Governor had not responded to a letter written by the Maryland Health Ethics Committee Network (MHEC), which letter included MHEC's request that the proposed guidelines developed by five healthcare systems in Maryland be made publicly available. The clinicians who were involved in the development of the guidelines have submitted a paper to the journal CHEST describing their intention, their process, and aspects of their guidelines. He said that paper had been accepted but had not yet been published. A pre-proofed copy of the paper is available from the CHEST website but that document does not provide much detail about the criteria for the allocation of scarce resources. His view is that there is an important public value in transparency about this issue and believed that the Council's support for the idea of transparency would be helpful.

Paul Ballard suggested if the Council should approve a letter to the Governor, that it should briefly support putting the proposed guidelines on the Maryland Department of Health's website. Hank Willner and Susan Lyons agreed.

Elizabeth Clayborne said she was able to present with Jack Schwartz on this topic. She said a review of these proposed guidelines is important because they have some serious shortcomings, specifically because the criteria used to determine the allocation of critical resources involves a lot of data that will not be available to an emergency physician. She explained that if there is actually a shortage of ventilators, an emergency physician like her would be the person who will have to decide whether to intubate a patient or admit a patient. Because of the way the criteria are set up, she said she would not have access to the data points she would need to make these difficult decisions. This will put practitioners like her in a difficult position if there are no available ICU beds or ventilators. She said there needs to be additional review from the State to see how these criteria are going to work in practice, and to make sure they are reviewed by clinicians from all the various areas in the hospital that are critical to implementing this policy, including the ER, ICU, and hospitalists. She said that palliative care practitioners will also need to be involved to make sure patients who do not get ventilators are appropriately treated when they don't have access to these life-saving interventions.

Hank Willner complimented Elizabeth Clayborne on the TED Talk video she created on the importance of advance care planning and said he had shared it with his family. She thanked him and said she had received a lot of great feedback from people. Paul Ballard had shared the video with Council members and other interested persons. Elizabeth Clayborne noted how critical advance care planning is going to be in the era of COVID-19, why it is essential for everyone to complete an advance directive, and why it is helpful for physicians and all medical providers. She asked that people share the video widely because it provides helpful information for both clinicians and lay persons. The video can be used as a jumping off point for discussions with family members and she is trying to circulate the video with different groups, including the Governor's office, to prompt people to see in a personal way why advance care planning is so important.

Dan Morhaim complimented Elizabeth Clayborne's video and said he has been working on a resolution within the American Medical Association that would urge physicians and other people in health to complete their own advance directives and thereby lead by example. He noted that if clinicians are not completing advance directives themselves, it is hard for them to ask others to complete them.

Paul Ballard recommended that people see Elizabeth Clayborne's video because he felt it to be captivating and covered everything on advance care planning that you would want to address. Ted Meyerson said it was the best video on this topic he had ever seen. Alan Eason said the video was very effective in connecting with the viewer in a different way. Jane Markley said she will be using the video as one of the highlights in her upcoming presentation on this topic to seniors on Montgomery County television. Elizabeth Clayborne expressed her thanks for the group's compliments and said she tried to make the video graphic in such a way as to connect with people personally so they could better understand what happens in real life and motivate them to complete an advance directive right away.

Dan Morhaim also mentioned that reading his recent book *Preparing for a Better End* is a good way to educate people about the importance of completing an advance directive. He also

mentioned a presentation on this topic he would be giving with Hank Willner for the Hospice Foundation on America.

Paul Ballard brought the discussion back to whether the Council should write a letter to the Governor asking him to post the draft guidelines regarding the allocation of scarce critical care resources on the Maryland Department of Health's website. There was a consensus among Council members in support of writing this letter.

Paul Ballard asked the Council whether it wished to plan anything for National Healthcare Decisions Day in 2021.

Dan Morhaim asked Christian Miele to request that perhaps the Governor, Lieutenant Governor, Senate President, and Speaker of the House complete their advance directives in the plaza in front of the Governor's residence and make a joint statement that would take 15 minutes. He had made this request to every Governor each year dating back to Governor O'Malley. He thought that given everyone's experience with the COVID pandemic, that perhaps this time Governor Hogan would be receptive to doing this.

Christian Miele asked whether the Council would write a letter to the Governor. Dan Morhaim agreed that the Council could do that but also believed that the Governor receiving something from someone within his administration would be very effective. Paul Ballard asked what Christian Miele might need from the Council. Christian Miele said an internal memo from the Council to him with the salient talking points and specific recommendations would be helpful. At minimum he could get the request to the Governor's Chief of Staff. Alan Eason agreed that the Council could do that. Dan Morhaim said all the information can be found on the General Assembly's website regarding House Bill 91 that passed in 2016, which bill required the Governor to annually proclaim April 16 as National Healthcare Decisions Day. Christian Miele said he would be willing to work with Paul Ballard on this.

Ted Meyerson asked whether a link to Elizabeth Clayborne's video could be included on various websites. Council members were supportive of those efforts.

Paul Ballard raised the issue of the electronic advance directives legislative report. The General Assembly had asked the Council, jointly with the Attorney General's Office, to submit a report by December 1, 2020 about how to increase the use of electronic advance directives. In response, the Council convened a workgroup of members and interested persons. He shared a draft report with the Council for their review.

Tiffany Callender said the workgroup considered many possible ways to increase the use of advance directives. The draft report starts with the background of what has been done in other places, what the data says about the completion of directives, and what have been the standard challenges. Under a section labeled Opportunities, the draft report presents various ideas about opportunities to increase the use of advance directives. She said that one example of such an opportunity is to have the existing one million advance directives in Maryland uploaded onto electronic medical record systems so that these advance directives are more easily communicated to providers. Another opportunity is focusing on strengthening the health care systems'

approaches to advance directives, such as a process for asking patients to prepare an advance directive. This could be similar to practices in the health care system in LaCrosse, Wisconsin. She said another opportunity would be to encourage health care practitioners to complete their own advance directives and asking health care systems whether they have their own process to ask providers and staff to complete advance directives. Another opportunity is to ask people whether they wish to complete advance directives when they renew their drivers' licenses or vehicle registrations. Or perhaps this question could be asked when people are seeking State benefits. And finally, another opportunity would be involving insurance carriers in the process by pulling some of the language from Dan Morhaim's 2016 bill that would require these carriers to communicate to their members about advance care planning.

The draft report ends with the five recommendations, including bringing carriers into the advance care planning process, revamping health care systems to embed advance care planning in them, encouraging health care providers to complete their own advance directives, and encouraging the Governor and other leaders and celebrities to promote completing advance directives by holding a public event on National Healthcare Decisions Day. Along those same lines, the report could be referenced in the Council's letter to the Governor to encourage him and other leaders to complete an advance directive in a public ceremony. Also, the draft report recommends that providers check CRISP (the regional health information exchange of Maryland) for advance directives.

Paul Ballard asked the Council to review the draft report and give the workgroup feedback. Tiffany Callender asked the Council to let the workgroup know if there are additional recommendations they would like to be included in the report.

Hank Willner asked how difficult it would be to get public service announcements about advance care planning. Tiffany Callender said the workgroup could add the recommendation in the report's public awareness and engagement section. Carrie Durham of the Maryland Department of Health said that at this time all their public messaging has to be centered around the COVID pandemic but thought it would be doable to include messaging about advance care planning. Paul Ballard noted that advance care planning is related to COVID. Tiffany Callender said that the Horizon Foundation created some short videos related to COVID and advance care planning, and why it is important to plan during a pandemic. She suggested that these are some ready-made content that might be available for public service announcements.

Elizabeth Clayborne said it is important for the report to make very clear to the consumer specifically what they need to do to put an advance directive on CRISP. She recommends to people that they use MyDirectives.com because it is easy to use and because in Maryland it is the approved electronic format [for linking to CRISP]. Jane Markley agreed and said the Voice Your Choice website is the best way to guide people towards MyDirectives.com. Tiffany Callender said the report does have a discussion of the Voice Your Choice and Speak(easy) Howard campaigns under the public awareness and engagement section, which discussion notes that both of these campaigns utilize MyDirectives as their action link to create an advance directive, but that this could be made clearer in the report.

Paul Ballard asked that the Council members review the draft report and give him any comments soon because of the pending deadline for the report's submission to the legislature.

Jeff Zucker, CEO of A/DVault, Inc (MyDirectives.com) said he is honored to help where they can. He said their draft letter is focused on best practices based on what their experiences around the United States and with the users of their website in over 50 countries, along with published research that they have cited. These citations should give the Governor the confidence that there is precedent for the bold actions being recommended in the draft report. This is a powerful opportunity and they believe Maryland is the most advanced of all the 50 states on IT infrastructure and stakeholder analysis for doing advance care planning right. Paul Ballard thanked Jeff Zucker for his very valuable contributions to the workgroup's draft report as well as the other workgroup members.

Jeff Zucker said that there is still a reporting challenge with CRISP in getting accurate data. He said there are certainly a lot more advance directives in the CRISP system than CRISP's reporting to the Maryland Health Care Commission identifies. He said that MyDirectives sends more advance directives to CRISP than they are reporting due to various difficulties CRISP is having in coding different data file types it receives that contain advance directives. He said that the data types need to be coded in accordance with health IT standards. He suggested that the Maryland Health Care Commission be given a little more authority to prioritize and work with CRISP regarding these issues to stay ahead of a rapidly changing IT industry.

Paul Ballard shared Shahid Aziz's question he submitted on Chat asking how many people from Maryland complete electronic advance directives on MyDirectives on a daily basis. Jeff Zucker (who lives outside of Maryland) said that were he to travel to Maryland, CRISP could not retrieve his electronic advance directive on CRISP, which is a flaw in the way that CRISP communicates with the MyDirectives database. He said that CRISP believes that its primary responsibility is to the citizens of the State of Maryland but lots of Marylanders may use their Florida mailing address for tax purposes. He said the Maryland Health Care Commission needs more authority to stay ahead of these practices so that a State agency is accountable rather than a private agency like CRISP

Jeff Zucker said MyDirectives gets hundreds of thousands of queries per day from people who are creating, updating, sharing, or querying to receive an electronic advance directive, or who are uploading a paper advance directive. Shahid Aziz said he recommends that when people complete an electronic advance directive they also have a hard copy they can carry with them. He said this is because retrieving an electronic advance directive from one institution might work great whereas retrieving it from another institution may be difficult.

Jeff Zucker said that since February 15, 2020 (as the COVID-19 pandemic was beginning to spread throughout the world), there has been a 27% increase in people who have gone on to the MyDirectives website to update their advance care plan. While having a paper copy is fine, he said that people want to be able to easily update their advance directive online. MyDirectives does provide a wallet card and the user can put the QR code on their driver's license, and then ask their insurance plan to put the QR code on the user's insurance card. Then, someone could

scan the QR code and retrieve the user's advance care plan. These proposals are part of what the workgroup set forth in the draft report to the legislature and A/DVault reiterates it in its draft letter. He said that they are happy to combine their letter with the Council's report, include excerpts from the letter in the report, or send the letter and report separately, whatever might be most helpful in the Council's efforts to see its recommendations implemented.

Hank Willner asked Jeff Zucker how he got a QR code on his insurance card. Jeff Zucker responded that the MyDirectives wallet card comes with a QR code and you can print out the MyDirectives QR code on a sticky label and place it on the insurance card. He said that insurance companies could print these out like they do for homeland security and for insurance verification issues. Having insurance companies add a QR code is not a difficult step and it is certainly something that MyDirectives would ask the State of Maryland to request that insurance companies do. Also, the Motor Vehicle Administration could do this for drivers' licenses, just as they do for organ donors.

Hank Willner said although he signed up for MyDirectives, he never received a card with a QR code. Jeff Zucker said he should go to MyDirectives.com and use the quick links to get a wallet card.

Sara Hufstader said Voice Your Choice is working with partners to create webinars. The last one they did was with the Archdiocese of Washington where they talked about the Catholic faith and looking at advance care planning in that context. Voice Your Choice talked about their platform and their training sessions. Next, she said they will be working with Cornerstone Montgomery to put together a webinar regarding people with mental health issues completing an advance care plan. She said there is a separate advance care directive for people with mental health issues. Based on her conversations with Cornerstone, she decided to raise the issue with the Council as something to think about in the future regarding whether there is a way to incorporate mental health care planning in the same advance directive form used for physical health care planning. That way, two different forms would not need to be completed. They will also be working with individuals with dementia. They will be reaching out to some organizations in Montgomery County about how to make it easier to handle advance care planning regarding both the mental and physical manifestations of dementia.

Dan Morhaim said that every County has a behavioral health advisory council. He chairs the council in Baltimore County and invited Sara Hufstader to contact him about giving a presentation to the advisory council. She thanked him for the invitation.

Alan Eason said he appreciated the valuable input, focus, and important contributions of members and guests at the Council meetings.

Marian Grant said that it is good news that members of the incoming Biden administration's transitional task force are palliative care friendly. Atul Gawande, who is on the COVID task force, will be playing a role in the transition, and one of Medstar's palliative care physicians is also on the transition team for the Biden administration. So, there are people moving into high level positions in the Biden administration that know the importance of issues relating to serious illness, advance care planning, palliative care, and hospice care.

There being no other issues to discuss, Alan Eason then adjourned the meeting.