

State Advisory Council on Quality Care at the End of Life

Minutes from the April 28, 2022 Meeting

Meeting time and place: April 28, 2022, 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; Gail Mansell; Tiffany Callender Erbeling; Christopher Kearney; Karen Smith; Christian Miele (Department of Disabilities' designee); Senator Ben Kramer; Geoff Coleman.

Others present: Marian Grant; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Steve Levenson; Stacy Howes; Sarah Oliveira; Michelle Ross; Niel Rosen; Hank Willner.

Chairman Alan Eason opened the meeting. The February 28, 2022 minutes were approved pending receipt of any corrections.

Senator Kramer said he went into the 2022 legislative session with the goal of improving opportunities for people to be made aware of the existence of advance directives and to have greater access to them. The bill he introduced in the 2022 session, Senate Bill 824, was consistent with the Council's recommendations contained in its report to the legislature in 2020 regarding how to get electronic advance care planning documents into the hands of Maryland residents and have them uploaded to a secure location where they can be accessed easily by physicians. In the 2021 session, he had introduced a bill to accomplish these same goals and it passed the Senate but stalled in the House committee with jurisdiction.

In the 2022 legislative session, Senator Kramer worked closely with his legislative colleague in District 19, Delegate Bonnie Cullison, who also serves on the House Health and Government Operations Committee where the bill was to be heard. It was a long process getting the bill fully drafted and ready to be voted on. As was the case in 2021, this bill passed the Senate with relative ease. In the House the bill slowed down a bit but in the end the bill was amended to become an exceptional work product that will accomplish what the Council hoped to do, that is, to increase dramatically the number of entities and individuals who will be reaching out to residents by sharing information on advance care planning with them, including physicians, Medicaid managed care organizations, health care facilities, nursing homes, and assisted living facilities, which entities will work cooperatively with Maryland's health care information exchange. The bill will also require the Maryland Health Care Commission to create additional standards and opportunities for advance care planning information to be shared and to develop a single electronic platform that will be safe and secure for everyone to upload this information, access it, and change their documents. He believed that the bill ended up being a very thorough and well thought out piece of legislation.

Senator Kramer thanked the many people who were influential in helping to get the legislation passed, especially Ted Meyerson, Jeff Zucker, Dan Morhaim, Elizabeth Clayborne, and Ben Steffen. He thanked everyone for their help and support in getting the bill passed. He thought the bill will provide a great basis to work from and will help move the ball forward

significantly on the issue of advance care planning. Ted Meyerson and Jeff Zucker thanked Senator Kramer for his work on the bill.

Jeff Zucker said that now the challenge is to execute what the legislation has authorized and to hold people accountable for compliance. He suggested that perhaps the Council could ask for updates from people who are responsible to implement the bill's provisions. He said one of the important parts of the legislation was to make the Maryland Health Care Commission the central point of contact on the issue of advance care planning. The diverse representation on the Council consisting of various stakeholders involved with this issue will help because they can monitor what is happening at the entities they represent, which monitoring will help to implement the legislation. For the Council's information, he also provided links on the issue of wrongful death suits in Maryland [More Lawsuits for Unwanted End-of-Life Treatment | Medical Futility Blog](#) because of faulty implementation of advance care planning. He asked the Council to look at how the Maryland MOLST form is being implemented and to make recommendations on how errors in its use can be avoided.

Paul Ballard read an email from Dan Morhaim about the legislation that read in part: "The Council and many of its members worked on this bill and - over the years - on previous versions to build consensus for passage finally this year. This legislation can be a model for other states. There is still implementation work to be done, but I think we are entitled to a "victory lap" right now. CONGRATULATIONS TO US."

Tiffany Callender Erbeding thanked Senator Kramer and everyone for their hard work in helping to get the bill passed. She said Speak(easy) Howard has crafted a best practices toolkit aimed particularly at healthcare systems while also including organizations and community partners. The idea is to leverage the success of the legislative session with more advertisements that will make people aware of the legislation's passage and give them tools to help them take advantage of what the bill authorized and to implement advance care planning. She shared the link [Best Practices \(speakeasyhoward.org\)](#). The toolkit explains what it means to be a health care agent and the benefits to both the health care system and nonprofit organizations in the community that want to help their community members with their care wishes. Using information that Speak(easy) Howard provided, their marketing firm wrote the toolkit to explain to a health care provider why they might want to pursue putting together an advance care planning initiative. The toolkit talks about how to update workflows in the Electronic Health Record to integrate advance care planning.

Paul Ballard discussed the passage of House Bill 378 which had been endorsed by the Council. The bill establishes a palliative care services workgroup under the auspices of the Maryland Health Care Commission to study the state of palliative care services in Maryland and to make recommendations regarding how to improve them. Marian Grant said this is great news. She works on a national basis with other states trying to do this and this is exactly the next step that is needed to be taken. She congratulated Peggy Funk and others who worked to get this bill passed. She wondered whether Council members and others can apply to be on the workgroup and how the Commission is going to choose the workgroup members in case anyone would like to volunteer to serve on the workgroup. Christopher Kearney said the bill describes the workgroup as being composed of people falling into four categories: hospice and palliative care providers; health care facilities; patient advocacy groups; and health insurers. He also wondered

about the process for appointing members of the workgroup. Paul Ballard said that interested people would have to contact the Commission and he was sure that they would share the process. He recommended contacting Tracey DeShields at the Commission. He said he would contact the Commission about the Council's interest in participating on the workgroup.

Christopher Kearney said that House Bill 378 asks the workgroup to examine the state of palliative health care services in the State of Maryland. And he said there was preliminary work completed years ago but he doesn't know if anyone has studied this issue recently to determine what palliative care services currently exist. The second task for the workgroup is to examine the existing capacity of palliative care services providers to now provide services or to increase their ability to provide services. Their third task is to examine any geographic area where significant gaps in palliative care services may exist. He is sure they will not have problems finding that such gaps exist in any locale in Maryland. Fourth, the workgroup is also to look for opportunities to collaborate with key stakeholders who are positioned to develop a strategy or plan for improving and expanding the provision of high-quality palliative medicine and care services. Fifth, the workgroup is to examine the feasibility of financial support for a long-term expansion of palliative care services, including insurance coverage. Sixth, the workgroup is to look at a plan for ongoing data collection for purposes of the monitoring and improvement of palliative care services. Seventh, the workgroup is to examine engagement strategies for educating the public about palliative care to empower individuals to make decisions about an individual's preferred care when faced with serious illness. And finally, the workgroup is to look at any other strategies that would improve palliative care services.

Christopher Kearney said that the workgroup will prepare a report containing its findings and recommendations to the legislature and the Governor. He said other states have improved their provision of palliative care services by conducting similar studies, for example, California, which added palliative care as a Medicaid benefit. So, there is a lot of opportunity in Maryland to improve the provision of palliative care services and the workgroup could help in these efforts.

Paul Ballard gave a legislative update. He said that beyond the bills already discussed, he did not see much legislation related to the Council's work. He did note that Senate Bill 559 passed regarding the recognition of supported decision making as an alternative to guardianship. He became aware of the bill because it amended the Health Care Decisions Act's provision regarding the Act's definition of "incapable of making an informed decision" to state that a competent individual should not be deemed to be incapable of making an informed decision merely because the individual uses supported decision making to communicate, just as is the case under current law regarding a competent individual using means other than speech to communicate. Legislative history created through testimony before the legislative committee clarifies the intent of the bill is to limit this exception to cognitively capable people who are having trouble communicating what they want but who use reliable means (such as supported decision making) to communicate.

Paul Ballard updated the Council on the issue of end-of-life care for prisoners. He said he was still trying to get information on that issue. He noted the previous contract between the State prison system and a healthcare services provider was publicly available on the internet but that he did not see the current contract with Corizon on the internet. He is making inquiries about its availability on the web because it would be far easier that submitting a Public Information Act request for the contract. He also noted that Peggy Funk had offered to invite a speaker from

Missouri to talk to the Council about what they had done there. Because Peggy Funk was not available for this meeting, Alan Eason and Paul Ballard thought it would be better to have her at the meeting when this presentation took place. So, this presentation will take place when Peggy Funk is able to attend the meeting and the next meeting will be scheduled accordingly.

Senator Kramer asked if this issue applied more to State prisons than to local jails. He asked if there was information that Robert Green, Public Safety and Correctional Services Secretary, might provide to the Council that would be helpful. Marian Grant said she would talk with Senator Kramer about what information would be helpful for him to seek from the Secretary. Paul Ballard said that mainly what the Council was interested in was getting a copy of the Department's contract with Corizon health services to review if the contract includes hospice care services and palliative care services and to see if there are any gaps in the contract regarding these services. If gaps exist, then perhaps the Department of Public Safety and Correctional Services should supplement the contract to provide those services. Senator Kramer said he was willing to reach out to Secretary Green about obtaining the contract for the Council's review to determine whether it includes certain services of interest to the Council.

Marian Grant said the prison population in Maryland is aging and Maryland does not have a robust compassionate release program. A bill introduced this legislative session meant to remedy that problem did not make it out of either chamber's committee. She said prisoners are often shuttled back and forth between the prison and the hospital, are not able to get released, do not get great care in either the prison or the hospital, and often die alone. She would like to talk to Corizon about how they are addressing the care needs of aging prisoners in other states with chronic illnesses and at the end of life, and to confirm whether Corizon is required to provide these services in Maryland under their contract, and if they are, what they are doing because not much of this care seems to be provided in jail.

Jane Markley raised the problem of an instance where a patient came to a large hospital with an advance directive and a MOLST form and the hospital took her paperwork and made copies of it to file in their files. She said they had no understanding of what CRISP, the State designated health information exchange, was, and that these documents could be available to them electronically. She wondered how we could improve the ability of facilities to recognize they have access to CRISP. She was concerned that all the work put into creating the ability to access these documents on CRISP is going to waste because people aren't aware of this option.

Jeff Zucker said an idea without execution is an illusion. He said that the hard work starts now that Senate Bill 824 was passed. He suggested that the Council could help with task forces that assist major hospital systems to make this a reality by making sure they change their workflows to utilize CRISP and to ensure access to advance care planning documents electronically. This will not occur simply because they are sent a link explaining the legislation. Instead, their managers must require that accessing advance care planning documents be part of their employees' workflow.

Christopher Kearney discussed the prison system issue again. He noted that despite there being many different jurisdictions, the great majority of Maryland prisoners are held in State prisons and probably most of the prisoners who may need hospice care services and palliative care services are in State prisons rather than local jails. He thanked Senator Kramer for his offer to talk with Secretary Green to be able to get the information that Marian Grant was seeking. He didn't think major hospital systems are the key to this problem but believed it would be better for

prisoners to be trained to be caregivers providing hospice and palliative care services. He suggested that a pro bono medical expert panel might be helpful in getting prisoners medical or geriatric parole as appropriate. He didn't think hospice care organizations or palliative care organizations are going to be that active in this area.

Marian Grant said there were several things the Council could try to do. She said there may be a policy in prisons that doesn't let prisoners have undue influence over each other and that this creates a barrier to having prisoners act as caregivers. Secretary Green could be asked whether that is still a policy because if it isn't, then that is something that could be done. Some of the hospice care and palliative care organizations then could train prisoner volunteers to provide this care to other prisoners. The Hospice and Palliative Care Network's board is exploring whether this is something that they want their members to do. Also, education could be provided to prison staff who do not feel competent about their end-of-life skills. Some members of the Council and interested persons could do some of this training on a pro bono basis. Once everyone decides this is a priority given that this aging prison population is not getting great care, there could be a multipronged effort focused on the biggest opportunities to help.

Niel Rosen expressed his appreciation for the Council's attention to this issue and agreed with the need for improvement in the end-of-life care provided in prisons. But he said it would also be great to have good care given in the prisons generally. As people get older there are lots of chronic diseases, multiple organ failures, diabetes, and other serious health issues that could be managed much better in prisons that result in unnecessary suffering. The Maryland Alliance for Justice Reform has been advocating for improved geriatric care and compassionate release in Maryland and may have advice regarding how Secretary Green might be able to help.

Christopher Kearney asked Niel Rosen about his efforts to revise medical or geriatric parole. Niel Rosen said legislative attempts have been to make the criteria less restrictive particularly as people age, noting that the likelihood of recidivism after 60 years old is very low. Compassionate release could also be expanded beyond being able to go home to die so that it also includes being able to be released to get better health care. He said someone from the Maryland Alliance for Justice Reform would be able to give more details. He also offered to reach out to a group in New York that could give the Council information about hospice care being provided in at least some facilities in that state. He said he could share that information with the Council by email.

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