State Advisory Council on Quality Care at the End of Life

Minutes from the December 9, 2021 Meeting

Meeting time and place: December 9, 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; Senator Ben Kramer; Gail Mansell; Christian Miele (Department of Disabilities' designee); Peggy Funk; Stevanne Ellis (Department of Aging's designee); Tiffany Callender Erbelding; Christopher Kearney; Yvette Oquendo Berruz; Sara Hufstader.

Others present: Ferdinando Mirarchi; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Stacy Howes; Julie Deppe; Jenny Kraska.

Chairman Alan Eason opened the meeting.

Ferdinando Mirarchi gave a presentation regarding his patented MIDEO card on which there is printed information regarding how to access a patient's living will, POLST form, and their health care agent, which card is accessible on the patient's phone or device. The MIDEO card links via a QR code to the patient's video advance care plan they created with their health care provider in accordance with a script used under their health care provider's guidance. The idea of the MIDEO card is to prevent unwanted overtreatments or undertreatments that are contrary to the patient's wishes.

Jeff Zucker said the key takeaway from Ferdinando Mirarchi's presentation is that a patient should prepare a video advance care plan and that people can upload at no cost a video advance directive prepared on MIDEO to MyDirectives.com (which is the only currently authorized system for the State of Maryland to link to CRISP, the State-designated health information exchange). MyDirectives.com has a button to upload a MIDEO video advance directive, and thus make it accessible to CRISP for any hospital in the State of Maryland. He said it is mind boggling that the research noted in Ferdinando Mirarchi's presentation showed that 80% of the time a living will is misinterpreted to be a DNR order. Gail Mansell said this statistic did not shock her because in her experience it happens very frequently that a patient is full code before she points out to the health care provider that there is a living will that would require a DNR order under the patient's current circumstances.

Tiffany Callender Erbelding asked how MIDEO is funded. Ferdinando Mirarchi is personally funding MIDEO and he said reimbursement from Medicare and commercial payers is available to health care providers for their advance care planning discussions with patients when using MIDEO.

Steve Glazer said MIDEO is a very impressive technology but is only useful if practitioners know it exists and asked whether there are plans to inform practitioners. Ferdinando Mirarchi said health care providers are instructed to educate patients and their health care agents to make sure they have the MIDEO card with them and to announce they have it in every health setting they come into. A letter is sent to the patient's health care provider informing them that

the patient has a MIDEO card and patients are asked to discuss their MIDEO card with their health care provider. He sends a letter to the patient's primary care physician, to a hospital's medical records administrator, and to the patient's attorney if the patient lists these people. They also educate patients to make sure MIDEO is on their refrigerators for EMS providers to see. They also educate academic settings, hospitals, and physician associations so that health care providers are made aware that the MIDEO technology exists. Jeff Zucker said that because of integration with CRISP, there should be indicators in the medical record accessible on CRISP showing that the MIDEO advance care plan is available on CRISP.

Peggy Funk introduced herself as a new Council member. She is the executive director of the Hospice and Palliative Care Network of Maryland and has been with the Network for almost 8 years. She is a certified association executive and her field is association management. She is honored to be on the Council. She offered to present to the Council in the future regarding what the Network does and to give a report to the Council on what is happening in hospice and palliative care in Maryland. She said that hospice utilization rate in Maryland is good and in line with the national average. She said hospice utilization declined somewhat during the Covid pandemic. Hospices are experiencing terrible shortages of nurses to the extent that some of the hospice houses have had to close or have been unable to serve the people they need to serve. But because there is such a dedicated workforce in hospices, she believes that Maryland should be able to overcome these challenges. She hopes the Council will be able to take a look at some of these challenges.

Gail Mansell introduced herself as a new Council member. She is delighted to be on the Council. She had previously served on the Council. She is an ordained inter-faith chaplain and is board certified in chaplaincy for palliative and hospice care as well as hospital work. She is the director of supportive care services at Atlantic General Hospital on the eastern shore of Maryland, a small 62-bed hospital and the only one in the resort area of Ocean City, which becomes the second largest city in the State during the summer months. She said many people have been escaping to this resort area during the Covid pandemic and thus the increased number of people no longer exists just during the summer months. She is interested in quality end-of life care. She has been working in chaplaincy for palliative and hospice care and hospital work through church organizations for almost 45 years, including the last 22 years at Atlantic General, where she created the palliative care and the pastoral care programs, as well as the implementation of advance directives.

Gail Mansell's goal in her work is make sure patients' spiritual and religious beliefs are honored and that their suffering and fear of dying could be eliminated to the best of her ability to allow peace and comfort to those in their final journey of their life, and to their families and loved ones. This goal eventually led to her learning about the enactment of the Health Care Decisions Act and becoming a huge advocate for advance directives. She believes that an advance directive is a tool, with all its flaws and shortcomings, that can empower people to make informed decisions about what their care should be, but she doesn't think it should stop there. Rather, advance directives require health care providers to become advocates for those patients. She said the presentation by Ferdinando Mirarchi and past presentations by Jeff Zucker continue

to validate the need for representation and advocacy for patients that complete advance directives. She said that she learns so much from everyone on the Council and that what she learns helps with her work. Alan Eason agreed, saying he learns a number of things at Council meetings from what people say. Gail Mansell said that at every Council meeting she has attended she has been able to take invaluable information back to her hospital.

Senator Kramer updated the Council on his bill to increase the use of advance directives. He said the Council had made very wise and well-written recommendations to a couple of the standing legislative committees, based upon which recommendations he introduced legislation in the 2021 session. His bill passed overwhelmingly in the State Senate but was stopped in the House of Delegates when certain entities expressed their opposition. These entities believed they were going to have an undue burden placed on them to help facilitate the completion of advance directives and to upload them to an accessible source so that emergency room physicians would have much greater access to advance directives, thereby enabling them to understand what care their patients want. The House sent the bill for study to a workgroup involving different interested groups and organizations. Those entities that were in opposition during the session are still in opposition. He anticipates that the task force will recommend significantly watering down the bill's effectiveness to the point that their recommended version of the bill will have little or no use or benefit.

Senator Kramer said he has already submitted a bill request to introduce the same bill he had introduced in the 2021 session. He is working with a delegate to see if there is a path forward in the House that will be satisfactory to his House colleagues and to see if they can make progress on the bill in the 2022 session. He valued Jeff Zucker's participation in the workgroup because he brings great knowledge and a helpful can-do attitude to the issue that counters the roadblocks presented by the opponents. Senator Kramer told the bill's opponents he was uninterested in the problems they presented. Instead, he asked them to present their solutions regarding how to accomplish the goal of insuring the greatest opportunity for Maryland residents to be aware of an advance directive, have access to an advance directive, and be able to upload their advance directive. Unfortunately, and unsurprisingly, he did not get that kind of response from the opponents. He is hopeful they will still make progress on the bill despite what the task force ultimately recommends in their report. He also said that Dan Morhaim has been spectacular in his efforts.

Jeff Zucker thanked Senator Kramer for his incredible leadership on this issue. He said it is amazing how hard it is to get easy things done such as letting a doctor understand something about the patients they are treating and giving people the confidence that the doctor knows something about the patient.

Alan Eason discussed the issue of chaplain visits with prisoners being treated at hospitals at the end of life. He referenced an article in the Mid-Atlantic Ethics Committee newsletter about a case where a prisoner in his sixties was terminally ill in a hospital and whether or not the prisoner should have been allowed to have a chaplain visit with him in the hospital. He wrote a commentary in the newsletter and noted there was also a helpful response written by a chaplain.

Senator Kramer said this is disturbing and asked whether this occurred in Maryland. Jack Schwartz responded this had occurred in a Maryland hospital but that he does not have a lot of facts. He suspects that the hospital did not want to go into too much detail. His suspicion is that the prisoner was awaiting trial in the custody of the local sheriff as opposed to being a prisoner who had been convicted and was held in State custody. Access was denied by the local sheriff to visitors and his suspicion is that the guard was instructed not to let visitors in and that the guard failed to understand that the chaplain was part of the hospital's palliative care staff and was integral to the palliative care received by the patient. In response to this issue, he suggested that the Council may wish to get information out to hospitals so that they know what to do when faced with such a situation and to get information out to State and local officials to avoid a repetition of this incident.

Senator Kramer said he will see if there are any existing State policies on this issue, either statewide or that govern local law enforcement units with regard to visitation by chaplains. Steve Glazer said there is a somewhat parallel case pending before the United States Supreme Court in which the prisoner had asked that a pastor be allowed to place hands on him during the execution. Susan Lyons said she works at Meritus hospital in Hagerstown and that they have a large correctional institution located near the hospital. She said they have never had any issues over the years regarding visitations by chaplains because they get a lot of good cooperation with State officials regarding these cases. Indeed, sometimes they get medical parole for these terminally ill patients. But she noted that sometimes for the local law enforcement agencies it is a different process altogether because such an end of life situation does not often occur for people in their custody who have not yet been sentenced.

Senator Kramer asked whether the prisoner might have been in a local jail because it was a minor offense or whether the prisoner was in custody while awaiting trial. Jack Schwartz said he did not know. He said the most helpful commentary in the newsletter was the advice given to hospitals not to just accept what the guard says at the door of the hospital room and to instead take the issue up the chain of command. He recommended that perhaps the Council could send a guidance letter to hospitals as to what to do should this problem occur. While it is hoped that this a rare occurrence, when it does happen it results in terrible care for the patient and will get a lot of people upset at the hospital. Thus, hospitals need guidance on how to handle this situation.

Christopher Kearney said this is not a common experience for him but he agrees that this is a horrible result. This also highlights the importance of a chaplain in palliative medicine. He said it has always been difficult for hospitals to accept chaplaincy as part of the medical model and it has been more successful in some places than in others. He said it is important to get a chaplain paid for and to recognize that a chaplain is integral to palliative care. He said a chaplain's work is often more important than what he does as physician.

Steve Glazer said he was recently involved in a case in which a family was refusing to allow an apnea test for an ICU patient who was declared brain dead. He noticed no one had asked if the family had any religious or cultural issues that might be involved in their decision and he suggested that the question be posed to them. Once the family consulted with their parish

priest with whom they had a long relationship, they agreed to the test and withdrew their objection. So, yes, clergy and chaplains in particular, can play an extremely important role.

Gail Mansell thanked Christopher Kearney and Steve Glazer for their comments regarding the importance of chaplaincy and noted she was able to make chaplains front and center of her hospital's palliative care program when she designed it. She offered to be a liaison to the Maryland Healthcare Committee Network chaplaincy meeting where this case first surfaced and noted she would mention to them that the Council discussed the issue and that she would recommend that they bring these issues to the Council.

Susan Lyons asked whether the State of Maryland has formally adopted the ASR (Allocation of Scarce Resources) framework. Jack Schwartz responded that they had not been formally adopted.

There being no further business, Alan Eason adjourned the meeting