

State Advisory Council on Quality Care at the End of Life

Minutes from the December 8, 2022 Meeting

Meeting time and place: December 8, 2022, 11:00 a.m., via video conference call.

Council members present: Christopher Kearney; Paul Ballard (Attorney General's designee); Jane Markley; Rabbi Steve Glazer; Tricia Nay (Maryland Department of Health's designee); Peggy Funk; Sara Hufstader; Gail Mansell; Tiffany Callender Erbeling; Christian Miele (Department of Disabilities' designee); Shahid Aziz; Senator Ben Kramer; Nicole Lopez de Victoria; Stevanne Ellis (Department of Aging's designee); Susan Lyons; Geoff Coleman; Elena Sallitto.

Others present: Nichole (Nikki) Majewski; Marian Grant; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Jenny Kraska; Sarah Oliveira; Katherine Ware; Scott Brown; Alexandra Baldi; Eleanor Tanno; Patricia Alt; Karren Pope-Onwukwe; Rene Mayo.

Newly appointed Chairman Christopher Kearney opened the meeting by saying there are a number of important things for the Council to do and he is happy to try and facilitate, and be useful to, the Council and Maryland, in furthering this work. He thought it would be useful for the Council to briefly review its history and mandate. He said the Council began in December 2002 after legislation was enacted establishing the Council. He said Jack Schwartz, Paul Ballard's predecessor, was instrumental in persuading the legislature to establish the Council as a permanent committee that would be available on a timely basis to advise "on changes in the law related to the provision of end-of-life care."

Christopher Kearney said the Council advises the General Assembly and State agencies. The Council's membership consists mainly of Governor's appointees and includes ex officio members representing the Attorney General's Office, the Maryland Department of Health, the Department of Aging, and the Department of Disabilities. And there is one representative appointed by the Senate President and there is one representative appointed by the House Speaker. The Governor's appointees are a physician, a nurse, a pharmacist with end-of-life care experience, a physician with long-term care experience, representatives from the health insurance industry, the managed care organizations, the hospital industry, the nursing home industry, the legal community, the hospice care community, two representatives from advocacy groups for end-of-life care, two representatives from religious groups, and two representatives of the general public.

Christopher Kearney said the duties of the Council are to (1) monitor trends in the provision of care to Marylanders with life-limiting illnesses; (2) study the impact of State statutes, regulations, policies, and other aspects of public policy on the provision of care at the end of life; (3) provide recommendations to the Office of the Attorney General, the Maryland Department of Health, the Department of Aging and other agencies of State government with respect to their activities affecting the provision of care at the end of life; (4) advise the General Assembly on legislative proposals affecting the provision of care at the end of life; (5) participate in or otherwise promote public and professional educational efforts concerning care at the end of life; and (6) carry out other duties as may be requested by the Governor or the General

Assembly. Looking at these duties, he realized that the Council has a fairly broad mandate and believes the Council might be more proactive in advising the legislature rather than simply reacting to already introduced legislation, that is, perhaps the Council could be more aware of pending legislation and be more helpful earlier on in the drafting of, and advising on, legislation.

Christopher Kearney asked Paul Ballard about the status of vacancies on the Council and Paul Ballard suggested this might be a good opportunity for new Council member, Nichole Lopez de Victoria, to introduce herself. Nichole Lopez de Victoria said she is the director of nursing at Fair Haven and has been working in hospice care and long-term care for about 25 years.

Dan Morhaim said the Council never had a vote where membership really matters and that Council meetings have always been open to anybody who wants to participate, and he thinks that is a good thing. He was on the Council officially for many years but then just kept coming to meetings after he was no longer a member. He said that people who aren't official members should never feel that they can't participate and contribute. Christopher Kearney agreed, saying the Council meetings are public, and everyone is welcome to participate, and their contributions have been very important for the Council.

Peggy Funk recommended the Council have an orientation for new members to give them an idea of the history of the Council and bring them up to date on what the issues are before the Council. Christopher Kearney thought that was a great idea, and indeed that is what prompted him to give the mini orientation at the beginning of the meeting. Paul Ballard said that he tries to remember to send a welcome email to every new member describing the duties and statutory mission of the Council, and what they can expect to happen as a Council member. But he acknowledged that more could be done to orient new members. Marian Grant asked whether only Council members are allowed to vote. Paul Ballard said that was correct. The September 19, 2022 meeting minutes were then approved.

Nikki Majewski of the Maryland Health Care Commission (MHCC) provided an update to the Council regarding its efforts regarding MHCC's efforts to coordinate the accessibility of electronic advance care planning documents in Maryland in accordance with legislation passed in the 2022 session. She said that in 2011, MHCC was awarded money from the Office of the National Coordinator and was tasked to explore options for facilitating the availability of electronic advance directives. Then in 2012, MHCC started a pilot to facilitate the exchange of advance directives through the State-designed Health Information Exchange, CRISP. In 2013, MHCC issued a Request for Proposals (RFP) and identified ADVault (dba MyDirectives.com) which was competitively selected to build an interface between its cloud-based advance directives repository and CRISP. That interface was launched in 2014. And then from 2015 through 2022, various legislation was passed that was aimed at supporting the greater diffusion of electronic advance directives and requiring MHCC to coordinate accessibility of advance care planning documents in Maryland. This included the State recognition program for MHCC to recognize electronic advance directive service vendors who would like to connect to CRISP. The MHCC adopted regulations that explained the process for developing criteria for State recognition and the most recent law removes the digital identity proofing guideline that was a

prior requirement. MHCC recognition is the prerequisite for a vendor to be permitted to connect to CRISP.

In terms of updates regarding MHCC's activities, MHCC has amended its regulations to align with the new law removing the digital identity proofing guideline and has also made some additional changes to the criteria for State recognition, including a vendor having to demonstrate adequate security and privacy controls for their systems. MHCC is increasing the frequency in which it collects some of that documentation from recognized vendors. Reporting, which was already happening on a biannual basis as it relates to ADVault and their reports to MHCC regarding the number of unique advance directives for Maryland residents in their repository, is now required on a more frequent quarterly basis.

Tiffany Callender Erbeling asked about the removal of the NIST digital identity proofing requirement (the National Institute of Standards and Technology Special Publication 800-63-2: Electronic Authentication Guideline or, if replaced, the replacement guideline). She was aware of the challenges having such a high bar for identity authentication was creating for vendors like ADVault, for example, requiring social security numbers, driver's licenses, passports, and the barriers these requirements create that discourage the submission of electronic advance directives that are permitted to connect to CRISP. She wondered what the practical changes for identity authentication will be in the absence of the NIST requirement. Nikki Majewski responded that the NIST requirement was burdensome for consumers who wanted to create an electronic advance directive. It will become a much more streamlined process, especially for the vendor ADVault. But there are still obviously safeguards to authenticate and make sure these individuals are who they say they are. And a lot of individuals don't necessarily use a third-party solution like MyDirectives.com. A large majority are going to their health care provider and storing a copy in their electronic health records system. And they are already authenticated to become a user of that system if they want to upload advance directives through their patient portal. MHCC has collected some data from hospitals and there has been growth in how consumers are sharing their advance directives with their provider, even just capturing health care agent information in the electronic health record system.

Tiffany Callender Erbeling asked what a consumer is being asked to provide instead of their social security number, for example, their date of birth, name, address, that is, what do one of the electronic advance directive vendors find to be acceptable for identification? Nikki Majewski said she is not sure exactly what that will look like because ADVault is still using the NIST requirements. She said she would confirm with ADVault and follow up with her.

Nikki Majewski talked about the consumer resource MHCC developed as a quick guide that overviews the importance of advance care planning and options for consumers to create an electronic advance directive. It also includes information on the Maryland Attorney General's website and the Maryland MOLST website for more information. She said Paul Ballard has been a great help in helping MHCC shape up the consumer flyer, including adding information on MOLST. Its content is also being reviewed with the aim of having it also serve as the Maryland Department of Health's advance directive information sheet that is required by law. She is looking forward to any tweaks to the flyer that Paul Ballard might recommend. She said several organizations in the State as well as health care provider organizations and payors have started to

share this flyer with consumers and to promote the flyer through social media and electronic newsletters. For example, the Motor Vehicle Administration (MVA) is featuring it on their website. Health care providers will give it to their patients so they can understand this process. CRISP has also included this information on both its patient and provider facing webpages, which includes links to MyDirectives.com. CRISP has also been sharing the flyer.

Nikki Majewski showed the Council two versions of the flyer with the same content that are formatted differently to accommodate individual preferences as to what version people want to share. There are versions that are also in black and white for provider offices who don't want to use color ink. Included with the flyer on MHCC's webpage is some sample language that people could use in their outreach to people when sharing the flyer. Gail Mansell asked where she could get the flyer. Nikki Majewski said the flyer is on MHCC's website and provided her with the link.

Paul Ballard said he is reviewing the flyer to see whether changes would be needed for it to comply with the statutory requirements for an advance directives information sheet. He said that more information is always good no matter what it is called. Nikki Majewski said that it was drafted with the spirit of the law's requirements, but they will make whatever changes are needed to make sure it can be considered to be the Maryland Department of Health's advance directives information sheet required by law.

Dan Morhaim said that most of the public doesn't know to go to the MHCC website. So, he asked what steps will be taken to put these flyers into more prominent places where people come in contact with State government, for example, when they apply for Medicaid or other benefits, or anything else in the Department of Health. He also asked whether MHCC would create a quality indicator for advance care planning applicable to health care facilities in the same way it does now for other health care services such as immunization, etc. He thanked Nikki Majewski for her work and said what MHCC is doing is a great step forward. Nikki Majewski said that the quality measurement issue is being explored by other persons at MHCC and she is happy to get an update on where they are with that in particular. She said MHCC is sharing the flyer with many people and is willing to share it with others. They have also reached out to libraries. Dan Morhaim said that libraries are great but also noted that local health departments have many people there to receive health care services who could also see the flyers.

Shahid Aziz agreed that a quality indicators requirement would be beneficial. Personally, he has been very disappointed that despite all the education he and others have provided, there is still the same low rate of advance directive completion. He said that even among medical community staff, and even for hospice care program staff, the rates of advance directive completion are not much better. Thus, the quality indicators would show what effect these educational programs actually have on increasing the rate of advance directive completion.

Gail Mansell recalled that a long time ago the Council has developed an advance directive card for distribution that was yellow with a lot of information on it. She didn't know if the card still existed. She said it would be really nice to know that any information that they have going out to the consumer is consistent with whatever other information they are seeing from the Council. So, she suggested that the Council research to make sure the old card is not still on the

Council's website. She said it would also be really nice if the flyer was on one of the websites where the Council refers people to information regarding the MOLST form and advance directives. She also wondered whether there is a way to make the optional Maryland statutory advance directive available in electronic form so that she could pull up this advance directive electronically and see whether it has been completed when seeing a patient in their hospital room, and if so, she wondered where these electronic advance directive forms would be kept.

Nikki Majewski responded that there is functionality available through the MyDirectives platform to enable people to scan these paper advance directives into the MyDirectives electronic platform. In fact, she said that this capability is a requirement for State recognition of an electronic advance directives vendor, that is, that there be a pathway to create an electronic advance directive or upload an existing version that might be in paper form. Gail Mansell said it seemed like a lot of work to get the paper advance directive into the MyDirectives platform but maybe it is easier than she thinks. Nikki Majewski said it should be just a simple upload once a person creates an account with MyDirectives. She said that a person can create an account with as little information as the health care agent's name and they can create a full advance directive and add a video, all being features required in the law and that are consistent with MHCC's State recognition program. MyDirectives added that upload functionality to become recognized by MHCC. So, there is the option to upload a paper advance directive onto MyDirectives that can be connected to CRISP. Gail Mansell thanked her and said she would try to do that.

Eleanor Tanno, a practicing family medicine physician in Rockville, Maryland, said that any practicing physician can lament quality measures because there's already so much burden on them in terms of things they are required to do, and said there are probably about 22 measures she is supposed to meet for her patients. One of these measures is Medicare wellness, that is, all of her Medicare patients are required to have a wellness visit at least once per year. It is hard enough to get a patient in for this visit and the wellness visit already has so many other required components. One of these components already is asking whether they have an advance directive. She doesn't think this requirement translates to anyone actually making an advance directive. She gives the paperwork for the MOLST form and the Maryland optional State advance directive to the patient if she has time, but she said to have a thorough discussion of these documents in a 30-minute appointment among all the other things she must go through with them is essentially impossible. So, given these challenges, she does not know whether having a quality measure would actually translate into more people completing advance directives.

Shahid Aziz said there is payment available to a physician for an appointment discussing advance care planning. Eleanor Tanno acknowledged that is the case but said many people in the general public don't feel comfortable talking about this. She briefly goes over the documents with patients and then she tells the patient she would be happy to make a specific appointment with them and their family members to go through the documents with them but realistically a very low percentage of her patients actually do this because they are uncomfortable with the topic. Thus, she thinks it is a great idea to add it as a quality measure but in terms of how that actually translates to practice, she does not think that will actually increase rates of advance care planning substantially. She thinks public service announcements are much more effective in getting people in the general public to talk about advance care planning.

Christopher Kearney noted he had 800 geriatric patients in downtown Baltimore and is quite familiar with the issue. He made a point of making sure he had an advance care planning discussion with every one of them. It took him years to do so. But he acknowledged that Eleanor Tanner is correct that it is a challenge.

Christopher Kearney asked Nikki Majewski if MyDirectives.com is the only source to create an electronic version of an advance directive. Nikki Majewski said they are the only vendor recognized and connected to CRISP. But she said a patient could ask their provider to store their advance directive in their electronic health record system. But she expects that once the MHCC regulations are adopted, there could be potentially other vendors that will seek recognition. She thinks that the previously existing identity proofing requirement was a deal breaker in the past for some vendors. So, some may be more willing to become recognized and get integrated with CRISP once the new requirements are adopted.

Paul Ballard asked if there are any identity authenticating requirements in the new requirements for the recognition of electronic advance directive vendors. Nikki Majewski responded that it depends on what electronic platform the vendor is using. Everyone's identity is authenticated if they're storing their advance directive in their provider's electronic health records system because there is a process that authenticates and makes sure that individual is who they say they are. A lot of this is occurring at the provider level at the point of care. Paul Ballard asked whether that is a criterion for recognition. Nikki Majewski responded there are privacy and security controls required. Paul Ballard asked if identity authentication is part of those privacy and security controls. Nikki Majewski responded that the specific identity proofing requirement under the NIST guideline is no longer required for vendors but there remain various required privacy and security components. Paul Ballard said he knew NIST was no longer required but he wondered if there continued to be a requirement for some type of identity proofing.

Scott Brown of ADVault said that ADVault's identity proofing is done through primarily two companies: LexisNexis and ID.me, both of which are well known companies. He said that requiring adherence to the NIST guideline is a substantial barrier. Most of the people who do advance care planning for example live in a nursing home, so they don't have their own utility bills. Also, their children get their phones for them, so they don't have a phone bill. They don't drive, so they don't have a driver's license. So, they really don't have these methods available to them for remote identity verification. When they go into the hospital, they verify their identity because they are standing right in front of them. Once the NIST requirement is gone, ADVault will continue to request first name, last name, date of birth. ADVault does make the driver's license and Social Security numbers optional to provide. They check those with their master patient index vendor to make sure these people exist. That's what it will continue to look like. As it stands now, Maryland is the only state in the nation that requires NIST identity verification. So, ADVault had to work with Maryland to create a work-around because users get very frustrated and aren't able to go through the steps. When they try it and if it doesn't work, ADVault gives them the opportunity to go around it. That process will go away, and it will be the typical account management tools that are seen on other web-based applications, that is, a verification email will go out that requires the person to click on a link. A text will then go out

with a code to the person's phone. These are the same kinds of access management and identity management techniques that happen with all the other apps that we all know. Those are being incorporated to substitute for the NIST requirement.

Paul Ballard explained the history of the NIST requirement for identity proofing regarding electronic advance directives. He said the reason for this requirement was to enable an electronic advance directive to be unwitnessed. This was a solution to the problem that all advance directives in Maryland, whether written or electronic, had to be signed in the physical presence of the witnesses in accordance with Maryland law at the time the NIST requirement was enacted. Since that time, the law has been amended to also permit the signing of an advance directive in the electronic presence of witnesses. He wondered whether there will now be a requirement for some sort of identity proofing in the absence of the NIST requirement. He asked Scott Brown whether ADVault does some sort of identity authentication. Scott Brown responded that they authenticate the existence of the person, and they use the techniques that he described, for example, a device can be linked to a person because we know that is the phone they carry around. They'll send a code to that phone or send a one-time link that expires to that phone or the person's email that allows the person to identify themselves rather than requiring a federal or State ID.

Nikki Majewski said that ADVault meets more than the minimum requirements for privacy and security, having more advanced privacy and security controls in place. Paul Ballard asked whether identity authentication requirements are part of the privacy and security requirements for MHCC recognition. Nikki Majewski said that MHCC removed the NIST requirements to be in line with the law, but that on the privacy and security side, an element of that is certification or accreditation from a nationally recognized body like HITRUST or EMAC and others. Gail Mansell asked when the new proofing identification requirements go into effect. Nikki Majewski said the law was to become effective in January, 2023, and MHCC regulations should be finalized the same month. So, the NIST requirements will be permanently removed from ADVault's website. But she said there are still controls happening behind the scenes to authenticate the identities of people who use the system offered by the website.

Christopher Kearney gave an update regarding the palliative care services workgroup convened by the Maryland Health Care Commission in accordance with law to study: (1) the state of palliative care services in Maryland, (2) the capacity of those palliative care providers to provide those services, (3) any geographic areas where significant gaps in palliative care services may exist, (4) 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; (5) the feasibility of financial support for a long-term expansion of palliative care services, including insurance; (6) a plan for ongoing data collection for purposes of the monitoring and improvement of palliative care services; and (7) engagement strategies for educating the public about palliative care to empower individuals to make informed decisions about an individual's preferred care when faced with serious illness. The workgroup has now met twice and a number of people in attendance at the Council's meeting are also a part of the workgroup. He said there is very little to report at this time, but a survey has been created that would go out to all Maryland providers, not just to palliative care providers, including nursing

homes, primary care practices, etc. They are using the Center to Advance Palliative Care's definition of palliative care. They modeled the questionnaire after one that was used in Colorado which had generated a lot of useful information. It is a very extensive questionnaire. Importantly, part of this questionnaire asks how palliative care services are being financed. The providers can bill for the additional services that are always thought of to be standard for palliative care which include social worker and chaplain services, but these additional services are not reimbursable for anybody. So, financing is going to be the main topic for the next meeting on January 9, 2023. Additionally, the survey asks about outcome measures, which will be interesting to see how many people actually have completed outcome measures because that requires a lot of human resources to implement. These outcome measures are complicated because they include such measures as days at home at the end of life, decreased emergency room visits, and decreased hospitalizations, all of which are hard to track. Finally, there is a broad question regarding what the greatest challenges are that palliative care programs face.

Peggy Funk said that the palliative care workforce has to be looked at because there is a terrible shortage of nurses and other types of healthcare professions that are going to be needed should Maryland create a palliative care benefit. She thought the workgroup is making some progress. She would like to see more consumer participation as to what patients' current experiences are like because that is very important. Otherwise, she thinks that the workgroup is hitting a lot of the targets that the bill discusses.

Christopher Kearney said that MHCC will follow up the survey with phone calls. He said the timeline is that a preliminary report is due in July, 2023, and a final report is due in November, 2023. He thinks the workgroup is a very good opportunity to see where Maryland is in terms of the current state of palliative care services regarding where the gaps are in services and how to improve the capacity to provide these services for all Marylanders. Shahid Aziz understood that the social work services given as part of palliative care are billable, but Christopher Kearney said that while they may be for mental health services, they generally are not reimbursable for palliative care services. Instead, the payments are supported by the institutional palliative care programs themselves. Rene Mayo, a palliative care social worker, said that a clinical social worker can bill independently, but because of bundled billing through a palliative care team, social work services usually fall to the bottom of the list because it is not worth the cost to bill for those services. That is why many outpatient palliative care teams choose not to bill for social work services. On the inpatient side, the hospital will not do it.

Marian Grant talked about concerns with the quality of end-of-life care for incarcerated individuals in Maryland. The prison population is aging, and prisoners have a higher incidence of chronic illness than the general population. Maryland has problematic medical parole policies and many clinicians like her who see patients particularly at the end of life see prisoners shuttled back and forth between the prison and the hospital. The Maryland prison system contracts with YesCare, formerly Corizon, to provide health care to incarcerated individuals. The contract has sections on chronic illness and end-of-life care, which sections talk about palliative care, hospice care, advance directives, and patients' bill of rights. However, the reality of the care actually provided does not seem to reflect what the contract requires in these sections. Thus, the Council formed a workgroup to focus on these issues and she is chairing that workgroup made up of

Council members and interested persons who wish to participate in the workgroup. She asked Rene Mayo to discuss a case that is emblematic of the challenges that the Council and the workgroup are seeing and are concerned about.

Rene Mayo talked about the case of a 25-year-old female at Jessup who had been residing at that correctional facility for several years. She was referred to hospice by her medical team when she was hospitalized but they ended up sending her back to prison. She had been diagnosed 3 years earlier with cancer of the liver and had undergone multiple rounds of chemotherapy and radiation. Her treating oncologist agreed there was likely no further benefit from treatment. She had a terminal prognosis with likely weeks to months to live. When Rene Mayo saw her in the prison, she looked like she was not being well cared for, that is, not receiving good pain management, not having her symptoms addressed, having shortness of breath, and not getting any needed medications or being undertreated with the medications she was getting. Everyone on the treatment team thought it would be appropriate for her to be in an inpatient hospice at least for some period of time to get the care she needed. But most hospices in the Baltimore region said they were not able to care for her, which was surprising given that she was dying of cancer, couldn't have any of her family with her, and was not getting appropriate treatment.

Rene Mayo works for Gilchrist hospice and is an MSW by clinical training. She is also an administrator, so she sees all the sides to this issue. She thinks it is important to talk about the fact that it took 6 weeks to actually make inpatient hospice care happen for this incarcerated individual when there were all kinds of people interested and pushing this forward. Gilchrist did end up accepting her and she learned what a great financial and human cost to the organization it is to admit someone in this situation. So, she thinks there are two parts to the issue: (1) incarcerated individuals are not receiving basic care and comfort at the end of life; and (2) these people need to be in a hospice in the community to have an appropriate place to be cared for and spend the last days of their life.

Rene Mayo said that there are the logistical challenges of trying to get hospice care to an incarcerated individual, including trying to explain a medical situation to a parole board consisting of a group of nonmedical professionals, which is difficult. The information these nonmedical professional board members are getting from the contracted health care provider were written in a way that even she couldn't understand with her background of 25 years in the field of hospice care. If she couldn't understand it, she felt it was very unlikely that a layperson could understand the language that was being used to demonstrate how ill this person really was. To remedy this lack of understanding, they had someone out in the field revamp it all and write back to the parole board and explain what was going on medically with this incarcerated individual. After that happened, they clearly understood that this patient was much too sick to be in a medical unit in a correctional facility.

Rene Mayo said that most hospice care programs are nonprofits that don't make a lot of money on the patients they serve because they are covering their costs and most of their additional funding comes through philanthropy, which donations are put into helping people that don't have money or don't have insurance. Gilchrist's mission is to serve as many people as they can that are in need. To serve one incarcerated individual patient in an inpatient hospice facility

increases a hospice's costs above and beyond that of a normal hospice patient so that an additional \$40,000 per month must be spent from the hospice's philanthropy money. That's a lot of money for one person for the hospice to incur on an ongoing basis. She would venture to guess that most hospices in the Baltimore region just could not afford that. Her concern from the hospice perspective is that if hospice care programs served incarcerated individuals as often as it needs to be done, they could not provide this care for many of these people because their funds would be spent too quickly.

She said that a hospice does not have the right things in place from a legal or regulatory perspective in the prison system to be able to provide all the information that is required to be shared. They must comply with victim's rights requirements regarding the provision of information, and thus they must share information with the victim's family regarding where the patient was being sent. They also have to incur the costly expense of insuring safety. So, they have to employ 24-hour security staff, which is a big cost (even though, for example, this patient was too weak to pose a security threat).

She said that when this patient was actually able to receive good care from the hospice treating her pain and symptoms, she looked much better. She had a young woman's body that beyond her cancer still functioned very well. Yet she was still dying. A person not in prison in her improved condition would normally receive hospice care services at home rather than be continued to be kept at a general hospice inpatient level of care. But they were not allowed to send her anywhere else unless they sent her back to prison because of the terms of the medical parole, which puts the hospice in a very difficult position because none of the hospice staff thought that was humane. But there is a limit to how many additional expenses the hospice can pay above and beyond what it reimbursed from insurance, even as much as the hospice community wants to provide these services to incarcerated individuals. No one wants to die in prison. This young woman said to Rene Mayo on the first day she came to visit her in the hospice unit that she didn't anticipate she would come out of prison, but that it was so meaningful to her to have her pain treated, to come through the doors of the hospice, and to see her mother at the end of her life. While this is the right thing to do, Rene Mayo said we have to understand all of the dynamics involved so that we can do what we need to do to actually see it happen.

Marian Grant said that this case highlights all of the issues and that we all want to improve care for people at any residence at the end of life or with serious illness but have to understand the magnitude of the challenge in all of these areas. It turns out that 2023 is kind of a handy and important year. So, first, it is going to be the first year of Governor Moore's administration and there will be a new Secretary of Public Safety and Correctional Services who will be appointed. Governor Moore has said that criminal justice is an area that he is interested in. At the same time, the contract the State has with YesCare (formerly named Corizon) is expiring at the end of 2023. So, the contract will be renegotiated, or a new vendor is going to be selected. There are reports and services that are supposed to be delivered in accordance with the terms of the contract and she is sure the Council would be happy to help anybody who is providing care for people with serious or end-of-life illness in the prison system to do a better job of that. But the Council needs to have a better understanding of what is going on. So, the prison

workgroup is recommending to the Council that it contact the Division of Corrections and ask to have confirmation of some of the information, that is, what is being done with regard to palliative care, hospice care, and advance care planning. The workgroup recommended that the Council write a letter to the Secretary of Public Safety and Corrections and make this request. She said the Council could also go the route of making a request for this information under the Public Information Act. She said there are people in the State working on improving medical parole, which is another area where there is opportunity for improvement, and that there probably will be a bill reintroduced in this upcoming session. The workgroup is monitoring that legislation and will come back to the Council with an update on whether that legislation is something they think the Council should support.

Christopher Kearney noted that he also met this patient and believed that if she didn't have friends that were in good places, she never would have gotten out of prison to receive these inpatient hospice care services. Most importantly, no one wants to die in prison and most of these people are not at much risk of causing much harm to anybody in the shape that they are in. So, medical parole does seem to be a very important part of this issue. He noted how the presenter from Missouri at the Council meeting in September had said how difficult the years-long process was to establish hospice services in Missouri's prisons. He said he is in favor of that as well for Maryland but believed that many of these incarcerated individuals could be served well in the community instead. He thought the Council could be useful in promoting changes to allow this to happen.

Paul Ballard said that there are various options for the Council to reach out to the Division of Corrections about this issue, including taking an informal route first or writing a letter, though if the Council requests documents in a letter that would constitute a Public Information Act request. Regardless of the option chosen, he felt it would be most effective to approach the issue in a helpful manner rather than in an adversarial manner.

Dan Morhaim said from his experience as a legislator and having heard a lot of discussions about parole, the Council can anticipate there will be testimony given from victims' families about people who might be going on parole, including medical parole. Christopher Kearney agreed, saying there are always other parties to be considered. Peggy Funk said that the cost for this is staggering and about 88% of the hospice care providers in Maryland are nonprofit. She said that the first step would be to see what the reports the contractor has to see if they are doing what is required of them under the contract. She made a motion to try to get these reports to get a good picture of what is going on.

Christopher Kearney agreed with Paul Ballard that the Council is meant to be a helpful advisory group and that he would like the Council to stay in that role. So, if the Council can ask the Department of Public Safety and Correctional Services what reports they are receiving from the contractor, that would be useful. Regarding the provision of care for chronic illness, palliative care and end-of-life care under the contract, Katherine Ware asked whether the contractor provides all the medical services or whether the prisons have their health care provider team provide these services. If there is a prison systems health care provider team, she asked whether the Council could get input from them as well. Marian Grant said that is one of their key questions, that is, who is providing this care. She said that from conversations she has had with

persons in the prison system, no one has the training to provide this care as they are not contracting with palliative care organizations or hospice care organizations. Because they don't have the expertise, she suspects that is why prisoners are sent to the hospital for issues that could have been handled at the prison infirmary if they were set up to provide those services. Thus, they end up getting fragmented and uncoordinated care by being sent back and forth to the hospital at the end of life. She wants to know who is delivering the chronic illness, palliative care, and hospice care services that are identified in the contract, what credentials they have, what training they have, and whether these services are offered to incarcerated individuals throughout the prison system, or whether they are just given based on which facility the person is housed and whether that particular facility has a physician with that particular expertise.

Peggy Funk made a motion to ask for all the reporting that is required by YesCare under their contract with the Division of Corrections. Marian Grant said that motion should also include asking for information as to who is delivering these services, that is, what is the nature of these services. Peggy Funk limited the motion to a request to seek information regarding palliative care and hospice services, and advance directives. Marian Grant said that under the contract, YesCare is supposed to be giving prisoners information on patients' rights and as part of that information, information on advance directives is required to be given. Anecdotally, prisoners have reported that no one has ever talked to them about advance care planning or about a patients' bill of rights, so she fears it may not a widespread practice to inform prisoners. but they don't know. She also wants the Council members and interested persons to be helpful and provide training for the prison staff, provide hospice care services in the prisons, and try to help persons get medical parole so that they can come into the community and obtain these services.

Jack Schwartz suggested that Paul Ballard find out who on Governor-elect Moore's transition team is responsible for corrections and let them know early what the Council is asking and what the background concern is, tell them the story that Rene Mayo told to the Council, try to get a meeting with that person, and put it on their radar early. Paul Ballard liked this suggestion. Marian Grant asked Jack Schwartz whether it is the current administration or the new administration that they should be contacting with these questions. Jack Schwartz said that the Council should assume that there is continuity, at least at the level of the people who are going to give the Council information. Thus, the Council should ask these questions early but should also make sure the new policy people via the transition team are aware of these questions.

Christopher Kearney asked Paul Ballard to draft a letter to the Department of Public Safety and Corrections for the Council's review. He agreed to do so. Marian Grant said she would make available the portions of the contract that are relevant to the Council's concerns to anyone who wishes to see them. Jane Markley seconded Peggy Funk's motion to seek information from the Division of Corrections. It was the unanimous consensus of the Council to send a letter to the Department of Public Safety and Corrections to seek information regarding the provision of palliative care services, hospice care services, and the education of prisoners regarding patients' rights (specifically with regard to their right to prepare advance directives), as required in the contract with YesCare to provide medical services to incarcerated individuals.

Jane Markley said that it came to her attention that there is some work being done at the Uniform Law Commission concerning the original Patient Self-Determination Act and making

changes to it at the federal level. Marian Grant said the Commission has been working on this and she is happy to share with the Council what they are discussing regarding potential revisions. The Commission is looking at what advance directives should cover, what is a health care agent, etc., and there is no requirement that states pass all of their recommendations, but many states do take a look at their work and say that maybe they should update their process or update their forms as well.

Christopher Kearney said he asked Peggy Funk if she wouldn't mind giving the Council an update on the issues of profit versus nonprofit hospices and fraud and abuse, given some of the recent articles about these issues. Peggy Funk said these fraud and abuse issues are happening on the west coast and are beginning to trend a little bit east. As background, she said that in the 1970's that a lot of states established certificate of need (CON) programs. What this did was to limit the number of hospice care providers that could come into a state. Most of the time it was focused on the need for the hospice care services.

Peggy Funk said that a trend started in the 1990's that a lot of the states did away with the CON requirement and consequently the number of hospice care providers proliferated. Also, she said that the Medicare benefit hospice care services that started in the 1980's made it more profitable for for-profit organizations, including venture capitalists, to provide these services. In California, just in Los Angeles alone, about 900 hospices have opened. That accounts for about 12% of hospices in the nation. And these include some very unsavory actors, a lot of them are not Medicare-certified. A lot of them are fly by night, engaging in fraud and abuse, and then closing up only to sell their license and open up somewhere else. Last year the California Department of Health placed a moratorium on opening up hospices or even expanding them. There will be no new hospices in California through 2023.

She said that in Maryland we are very fortunate that about 84% of hospice care providers are nonprofit and are small community hospices committed to their communities and beloved by them. She said that you don't hear about fraud and abuse in Maryland or even hear complaints about hospice care providers. But the Maryland Hospice and Palliative Care Network has always advocated for protecting the CON requirement for hospices. The Network wants to make sure that new hospice providers have a good record of quality care and no history of fraud and abuse. She wanted to let everyone know that the Network will fight to keep the CON requirement. When someone applies for a CON, the owner of the hospice is vetted so they know who actually owns the hospice. She thinks the reason that Maryland enjoys a low rate of fraud and abuse is because Maryland has a lot of nonprofit hospices and because of the CON requirement.

Christopher Kearney said that he and others who are engaged in hospice work have witnessed the percentage of for-profit hospices grow and he said it is scary how many for-profit hospices have been established. He worried that all legitimate hospices would be unfairly viewed because of the actions of those that engage in fraud and abuse, and this is going to continue to be a topic for discussion. Peggy Funk said she does not want to castigate all for-profit hospices. She said there are just some bad actors out there. And she said to please keep in mind that 70% of hospices nationally are for-profit. So, it is not realistic to close all hospices that are for-profit. But she said that there is a need to create some guardrails and she thinks the CON does that as far as really vetting who comes in as a new hospice provider.

Marian Grant said that at the federal level they are taking a serious look at this problem. Christopher Kearney thanked Peggy Funk and Marian Grant for keeping the Council informed on this issue and said that the Council would be interested in hearing further developments regarding this issue. Dan Morhaim said he had visited a suburb of Los Angeles recently and saw 5 hospices in the neighborhood, visited them and just started asking questions, and he found exactly the negatives that Peggy Funk had pointed out, that is, they clearly didn't know what they were doing, and that they could barely even answer the most basic questions he posed as a potential innocent consumer. Christopher Kearney said the article he referenced was published in the New Yorker and in Politico.

Christopher Kearney talked about a discussion group formed by the National Academy of State Health Policy. Peggy Funk and he participated, and their topic was increasing palliative care access for Medical Assistance patients. The survey being done by MHCC palliative care workgroup will be helpful in identifying where the gaps are in the provision of palliative care services in Maryland.

Christopher Kearney asked people attending the meeting whether the aid-in-dying bill would be reintroduced in the 2023 legislative session. Dan Morhaim said he is pretty sure that the bill will be reintroduced, and Peggy Funk agreed. Christopher Kearney asked Paul Ballard to state what the Council's position on the bill had been in the past. Paul Ballard said that when the bill had come up before, the Council has been divided in the same way that the general public is about the issue. At one time, a majority of the Council voted to oppose it for various reasons but also includes a dissenting opinion in support of the bill in its written testimony given to the legislature. He hasn't seen the new bill but imagined it would look the same as before. Peggy Funk said that she believed that Compassion and Choices will be introducing it again this legislative session. Christopher Kearney asked Paul Ballard to update the Council if and when he sees the bill introduced. Jack Schwartz said he didn't know anything about a bill this session, but he believed this is an instance where the Council cannot bring anything new to the table and it doesn't help the legislature to find out that the Council splits on this issue. He believed the Council would not be contributing any new thoughts to the debate. So, while the Council should monitor what is going on, he did not think the Council should spend a lot of time on bringing the Council's view to the table because it would not be helpful. Christopher Kearney agreed.

Elena Sallitto said that Maryland's policies historically have favored institutionalization of people who need long term care. So, instead of allowing people to die at home, Maryland has structured things to essentially force people to go into nursing homes separated from family and forced to die in the institutions. The private bar has been working with the legislature for over 20 years to try and change that. It is an incredibly slow process, and they are making headway but what is alarming is that the ownership structure of nursing homes seems to be changing in a very dramatic and not good way for the residents. They are increasingly being owned by private equity companies and they are putting profit before care. These outfits are coming in and buying up large numbers of nursing homes and putting them under a single umbrella. So, you have a lot less competition, there's no choice, and there are now also issues with staffing. And she believes quality of care is getting unbelievably bad and she is hearing horror stories of what is going on in the nursing homes.

Elena Sallitto would like the Council to write a letter to the new governor to put the fate of these old people at the top of the agenda. She said these are people that have no voice and are the most vulnerable of the vulnerable and unless they have an advocate who is going to be able to speak for them loudly, they are going to get unnoticed. They don't vote, especially if they have dementia. So, they are ignored. So, if there is anything the Council can do to keep them present and in front of decision makers such as the governor, that would be great. Christopher Kearney said her concern is correct and asked her to send a letter outlining what she said so that the Council could have a little more opportunity to think about the issue. Elena Sallitto said she would be happy to do that.

Peggy Funk said there are several organizations that represent the nursing home industry in Maryland, including LifeSpan, HFAM, and Leading Age, and she asked Elena Sallitto if these organizations have been approached, and if so, whether there has been any response from them. Elena Sallitto has considered whether or not her organization, National Academy of Elder Law Attorneys (she is head of the local chapter) should reach out to these organizations. She said that the issue of home-based care has been her organization's number one legislative issue for 20 years. She is thinking about reaching out to these nursing home industry organizations to see what they say and now that Peggy Funk mentioned it, she will. Peggy Funk said she would be happy to give Elena Sallitto the contacts for any of those organizations because the Hospice and Palliative Care Network sometimes collaborates with them. Elena Sallitto thanked Peggy Funk for that.

Christopher Kearney raised the issue of the Council holding its meeting in a hybrid form of in-person and video conference for future meetings. He proposed to hold a hybrid form of the meeting. The Council's consensus was to have hybrid meetings in the future.

There being no further business, Christopher Kearney adjourned the meeting.