

State Advisory Council on Quality Care at the End of Life

Minutes from the September 22, 2023 Meeting

Meeting time and place: September 22, 2023, 10:00 a.m., via video conference and in-person at the Office of Health Care Quality, 7120 Samuel Morse Drive, 2nd Floor, Potomac Room, Columbia, Maryland 21046-3422.

Council members present: Christopher Kearney; Paul Ballard (Attorney General's designee) (in-person); Jane Markley; Peggy Funk; Gail Mansell; Tiffany Callender Erbeling; Elena Sallitto; Alan Eason; Donald D'Aquila; Susan Lyons; Sara Hufstader.

Others present: Steve Levenson; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Kathy Ware (in-person); Stacy Howes; Sarah Oliveira; Nancy Denebeim; Marian Grant; Tashi Taliaferro; Jenny Kraska; Ryan Wilson; Lisa Belcastro; Tammy Turner; Rachel Sherman; Christine Pfleiger; Debbie Ahl; Jayme Levy Duva; Scott Brown; Mike Munoz; Cathy Pauley.

Chairman Christopher Kearney opened the meeting. The June 13, 2023 minutes were approved.

Jane Markley updated the Council regarding the National Healthcare Decisions Day 2024 workgroup. She asked Dan Morhaim if he would be willing to do what he usually does in relation to promoting National Healthcare Decisions Day, that is, writing a letter to officials in the State of Maryland. Dan Morhaim said he was willing to do whatever he could to help. Jane Markley appreciated his help. She got the sense that the Maryland Health Care Commission was not doing anything to promote National Healthcare Decisions Day. She said the Council workgroup will need to keep looking for opportunities and try to determine a good role for the Council in promoting National Healthcare Decisions Day. The workgroup's intent is to focus more on the healthcare providers this year.

Christopher Kearney asked Dan Morhaim if he had any comments about how the Council may support National Healthcare Decisions Day. Dan Morhaim said it is important to keep doing outreach activities and to remind everyone that the Day is officially recognized by State law. He writes the same letter to the same State officials each year suggesting that they have a public advance directive signing ceremony with their spouses and to perhaps include celebrities. Christopher Kearney asked Paul Ballard whether the Council could prepare a similar letter asking officials to express public support for, or publicly sign advance directives, as part of a National Healthcare Decisions Day event to help promote their use. Paul Ballard responded that sending such a letter would be within the purview of the Council. Christopher Kearney asked that Dan Morhaim share with the Council the letter he sends, and the letter could be distributed to the Council to consider. Dan Morhaim agreed to send a version of the letter to Christopher Kearney and Paul Ballard.

Christopher Kearney said that in May 2023 the Council wrote a letter to the Maryland Health Care Commission (MHCC) requesting information and certain statistics, including the insurance carriers' first year of experience with the law promoting advance directives and what they plan to do differently next year. The Council asked about the Motor Vehicle Administration's part in complying with the legislation's call that advance directive documents

be identified on all drivers' licenses. The Council asked about surveying hospitals and doctors to find out if their access to advance directives is improving, and the Council asked about the general demographics for CRISP (Chesapeake Regional Information System for our Patients), the State-designated health information exchange. The Council did get a response from MHCC in the middle of the summer saying that they did not have all those details, but they were coming out with a more generalized document, which turned out to be the "Spotlight" document on electronic advance directives that the MHCC sent to Paul Ballard, who then distributed it to the Council.

Paul Ballard noted that one of the highlights of this document was how much it showed that the vast majority of advance directives stored in electronic health records are in hospital systems' records, and that very few of these advance directives are also put into the MyDirectives website to connect with CRISP. The MHCC also provided a letter from the Motor Vehicle Administration saying it was acting based on the legislation enacted in 2022. He said the MHCC has done a lot with the public promotion of advance directives. MHCC created an advance directives information sheet that seems to be a little more user friendly than the old information sheet, which new information sheet is now on the Attorney General's website as well as on different State agencies' websites. So, MHCC has been working a lot on the promotion of advance directives. Various responses from Nikki Majewski and other MHCC staff addressed the Council's questions contained in the Council's May 2023 letter.

Christopher Kearney also noted the Spotlight's chart showing that the overwhelming majority of advance directives were in hospitals' electronic health records systems. He asked if anyone knew when these advance directives would become generally available on CRISP.

Scott Brown of AdVault responded that AdVault (MyDirectives.com) has multiple initiatives going on in Maryland and in the District of Columbia. Medstar is its largest contributor and has put several thousand advance care planning documents in AdVault's MyDirectives system every month. That document search is available to all the other hospitals, including Luminous, Johns Hopkins, and Greater Baltimore Medical Center, but Medstar has been the most active in taking advantage of the MyDirectives' system. AdVault has been working with CRISP quite a bit and has been communicating with the Maryland Secretary of Health about the possibility of embedding one of their clinician-facing tools which is called "MyDirectives for Clinicians" into the CRISP context-provider world and making this tool available at very little cost to healthcare providers across the State. They are speaking with MedChi representatives too about this initiative. He believes this would be a very effective tool to improve the un-siloing of the advance care planning documents that already exist in hospitals' EPIC and Cerner electronic health record systems. He said AdVault also has a privileged relationship with Cerner called Oracle Health.

Scott Brown said AdVault is also working with the Maryland Department of Health's Cancer Prevention and Treatment program. And they are getting ready to start a pilot program at Luminous Health using MyDirectives for Clinicians to fulfill advance care planning and upload existing documents. That program is also available to other hospitals. These initiatives will hopefully lead to the transfer of advance care planning documents from the hospitals' EHR systems to CRISP through the MyDirectives registry and depository. In Google Meet Chat,

Susan Lyons wrote “we are meeting with Louis Raya with ADvault on October 12 to assure our Meritus Epic ACP docs (approximately 25% of in-patients over age 18) are accessible to other hospitals/clinicians.” Scott Brown said while he is not personally familiar with that project, it is one of many initiatives taking place in Maryland. He does see a continuing challenge with some of the healthcare payors in Maryland. He thinks there is willingness there, but he would like to see them more involved in some of the things that are happening such as the reporting and analytics. They will keep making efforts to encourage involvement by the payors.

Christopher Kearney said although he was disappointed in the small numbers in the overall system, 384,000 advance directives within the hospital framework is still quite a lot of progress from the much smaller previous number of advance directives in their EHRs. So, actually, he is encouraged by the improved flow process. For example, he found it to be encouraging that the hospital he sometimes works in on the Eastern Shore reported to him that almost 40% of their palliative care patients already have existing advance directives. Paul Ballard agreed it is very positive that we are getting a lot of advance directives into the EHRs. He said that the ultimate goal is that they all be accessible in one place, but at that least we are getting a lot of them in the healthcare system.

Christopher Kearney talked about the palliative care workgroup convened by the MHCC to review the state of palliative care in Maryland. Part of what the workgroup is looking at is to determine what is going on in community-based palliative care in Maryland in addition to the care being received in hospitals. They had their final meeting on August 31, 2023. They prepared a draft of six recommendations that will be sent to the legislature in November. A final version will be approved by the MHCC in October.

Christopher Kearney said that the first two recommendations concern education. Recommendation Number 1 is public education, and the Council is cited in the report as one of the groups to work with to develop comprehensive evidence-based education regarding palliative care. The Council, along with community associations, the Maryland Department of Aging, and the Maryland Department of Aging’s Maryland Access Point (MAP) [whose specialists work with caregivers, professionals and all individuals with long term care needs to plan, identify, connect, and assist with accessing private and public resources for long term services and supports]. In terms of public education, he thought it was good to include MAP to help expand their services to also connect these people with palliative care services. The last recommendation was to seek funding to launch evidence-based palliative care public awareness campaigns, which he and others emphasized the great importance of at the workgroup meetings.

Recommendation Number 2 was to increase the number of trained and credentialed healthcare professionals in palliative care and to perhaps add a palliative care requirement in educational programs for healthcare professionals, including even medical residencies. They were hoping to work with the Maryland Higher Education Commission on this issue. They also recommended using the term “workforce valley” to emphasize there is a hole in terms of available palliative care providers, not just in Maryland and not just in the community. They also recommended policies and payment reforms be implemented to promote growth and sustainability of the palliative care workforce, including efforts to promote, support, and expand physician and advanced practice nursing fellowships, including loan forgiveness at academic

institutions in the State. They also recommended that relevant health occupation licensing boards establish palliative care continuing education requirements. The most important aspect of

Recommendation Number 3 is financing. So, they recommended: (a) a financing mechanism for palliative care services, through a Medicaid State Plan amendment, modification of the Total Cost of Care Medicare model, and other insurance mechanisms; (b) to integrate palliative care services within Maryland's Medicaid State Plan and to require Medicaid Managed Care Organizations (MCOs) to provide a palliative care benefit with defined services under their managed care contracts; (c) to continue work with the National Academy for State Health Policy's (NASHP) Serious Illness Institute to explore ways to fund palliative care benefits statewide, including an exploration of funding models used successfully in other states; and (d) to review the expansion of the PACE program (Maryland Program of All-Inclusive Care for the Elderly) to include palliative care benefit as a required benefit in that program.

Recommendation Number 4 was about community-based palliative care. He said this workgroup was really formed to focus more on palliative care services in the community rather than palliative care provided in the hospital setting. The workgroup recommended that a broad and funded palliative care coalition, including providers, consumers, MHCC, Maryland Department of Aging, and the State Advisory Council on Quality Care at End of Life, should develop a strategy for the development, promotion, and sustainability of community-based palliative care services. And the workgroup mentioned that this should be a funded coalition. He said he knows from previous experience that you can coalesce a lot but if you don't have funding, it is very hard to make these things work or be useful. He hoped that they would create this palliative care coalition and that there is some funded mechanism for it. The workgroup talked about contacting the primary doctors with the Maryland Primary Care Program (MDPCP) about integrating palliative care into primary care, which would be a great idea. Again, people would have to be reimbursed for providing palliative care services. The workgroup talked about innovative funding, including alternative payment methods and the extension of community health through hospice and home health agencies.

Christopher Kearney said that the last two recommendations were about quality improvement. He said there's always a concern that if you build a program, then who's watching how they're doing and what are the quality standards. CAPC, the Center for Advancement of Palliative Care in the United States, is probably the leading organization for quality standards, along with the National Consensus Project for clinical practices in palliative care. So, the workgroup recommended that any program also have some requirements through one of these accrediting organizations. They weren't talking about licensing directly, but accreditation related to CAPC or to the National Consensus Project. Thirdly, it was to continue to build and update the palliative care provider directory, which did not exist until the workgroup and the Maryland Healthcare Commission had started that work. He felt these were good activities for quality improvement and maintenance. Finally, they agreed to continue to survey the providers across Maryland regarding the state of palliative care on an every-other-year basis, but probably using a little more streamlined survey than had been sent out this time. But knowledge of where the palliative programs are and who is doing what is helpful to all people involved in the care of seriously ill Marylanders.

Marian Grant said that the Council needs to figure out how active it wants to be in the next step of this process. The legislation calls for the workgroup to come together, to survey the field, and to develop recommendations. But then what? So, she thinks that one of the recommendations is that the State explore establishing a serious illness care coalition. It has to be figured out what group is going to continue doing this work, which will obviously include the Hospice and Palliative Care Network. The other thing that the Council has to think about is that other states that have pursued a Medicaid benefit have used a very inclusive stakeholder information gathering process.

Peggy Funk said the Council should be very happy with how the workgroup turned out. She thinks the workgroup's recommendations are really great. It also really highlighted the need among stakeholders to get a palliative care benefit in place. First, the Council will have to make sure that the Maryland Health Care Commissioners do approve the report. And then it goes back to the legislature. She thinks we could be looking at opportunities because when you start to legislate these types of benefits, you get a little faster movement than just having coalitions that are talking about them. Legislation could be put forward to create a coalition with funding and to get the backing of all the key stakeholders in place to push this coalition forward. The Council can see how things develop with the workgroup's report to the legislature.

Gail Mansell said if the Council decides to embark on this project which she supports, she suggested that perhaps the Council should consider changing its name because the Council's current name suggests that you can only have palliative care if you're dying. Christopher Kearney agreed and said the name no longer seems to be modern or appropriate in some ways and is a little bit self-defeating. He said that the Council often considers the care of seriously ill patients for many reasons, not just the care given at the end of life. He asked Paul Ballard what the likelihood of going to the legislature and having the Council's name changed. Paul Ballard said that if the only thing the bill did was change the Council's name, he didn't see how it would be controversial. But then again, there were bills in the past that he thought were not controversial that ended up being controversial. Christopher Kearney asked how the Council could get such a bill passed that suggests that the Council has a role regarding seriously ill patients in Maryland and not exclusively patients who are at the end of life.

Dan Morhaim said he could answer that question, having served in the General Assembly for 24 years. He said that the Council should come up with 2 or 3 names, a little list, and then find a sponsor and put the bill in. It would then go to bill drafting. It would be pretty straight forward, though he agreed with Paul Ballard that you never can tell what will be controversial. He said this would be the time to do this for the 2024 legislative session. He volunteered to help with taking these preliminary steps. Marian Grant agreed that this is a great idea. She said that the Council has talked about this issue before and now the Council has great resources like Peggy Funk and Dan Morhaim and champions in the legislature. She thought it would be worth giving this a try. Dan Morhaim said not to expect the legislator to come up with the name for the Council. The Council should suggest 2 or 3 choices for the name so that you have alternative names in case someone objects to the name. Kathy Ware said the prefile date is November 1. She suggested Senator Lam as a sponsor, noting that he is a doctor. He is pretty open to listening. She also suggested Senator Beidle and Delegate Pena-Melnyk. Dan Morhaim said that Senator Lam had previously been an intern in his office when Dan Morhaim was a Delegate and he did some

research for the original book that Dan Morhaim wrote in 2020, and so he is very familiar with the topic. He is a State Senator and a Chair of Preventive Medicine at Johns Hopkins. He would be an excellent choice as would be Senator Kramer and Delegate Cullison, who both carried the more complicated bill through the legislature in the last couple of years, should also be given an opportunity to be a sponsor as well as a legislative courtesy because of their work on those bills. A workgroup was formed to look at this issue consisting of Marian Grant, Kathy Ware, Dan Morhaim, and Gail Mansell, to be led by Marian Grant. Dan Morhaim noted that you don't have to pre-file a bill.

Peggy Funk talked about the National Academy for State Health Policy (NASHP) grant workgroup's third meeting. She said it is a great dynamic group made up of members from 6 states, including Maryland, Ohio, Colorado, Maine, Texas, and Washington. This meeting was held to give everyone the opportunity to talk about what they have been doing in their own states. She heard about the variety of things states are doing, for instance, Colorado seems to be more focused on a palliative care benefit for children, Maine is doing similar things to what Maryland is doing but they are a little bit farther ahead of where Maryland is. She and Marian Grant told them about the completion of the Maryland palliative care workgroup's report and its draft recommendations. Incidentally, Peggy Funk complimented Linda Cole of the MHCC on her outstanding job giving this report. She said that the MHCC has been very collaborative for the workgroup to work with. The NASHP meeting then broke up into workgroups and in those workgroups the states' representatives talked a little bit about their process. For instance, Maine is actually working on developing their palliative care benefit, which she thinks will probably be Maryland's next step, and talking about who should be included. Ohio talked about this as well, saying it was very difficult to include an interdisciplinary team because the cost was pretty high. Also, it is very difficult in a rural community to fill these positions. So, they heard from the states regarding their challenges and their successes. And they shared what they are doing in Maryland.

Marian Grant said that key recommendation of Maryland's workgroup is to have a Medicaid benefit but there are a number of ways to actually go about doing that. She said that it is fortunate Maryland is part of this NASHP grant because they are giving Maryland free actuarial analytic and financial support, money that the Maryland Health Care Commission and that Medicaid doesn't have, and that no one has. That was the problem in Maine which passed legislation a couple of years ago to approve a palliative care benefit, but they had no way of actually making that happen. They are now going through that process by using the NASHP tool. So, while Maine is ahead of Maryland in terms of legislation passed, they are still in the same analytic stage that Maryland is in. Maryland is going to need to take a look at the patient population, the kinds of services, the payments for the services, what the savings might be, because nothing is going to be approved anywhere unless it is either cost neutral but ideally saves money. The good news is that the data says that palliative care saves money by keeping people away from unnecessary or unwanted treatment. That analytical work is just starting in Maryland and then we are going to have to work as a subsequent group, perhaps a coalition, to figure this out.

Marian Grant said that Hawaii decided not to do a Medicaid waiver but instead did a state plan amendment, although they had input from CMS. Other states have done Medicaid waivers,

which is a very formal process. So, there are many different routes to take. So, while they have decided they want to go ahead with a benefit, she is not sure if it is exactly clear which route they are going to take. They will keep the Council posted and the Council can be involved in a process that is probably going to take several more years looking at the analytical data and maybe getting legislative support, and stakeholder engagement for many more people. If the Council supports a Medicaid waiver, Maryland will have to apply for a Medicaid waiver benefit and have it approved. So, this is not going to happen any time soon. But she thinks it is good that Maryland is doing better than she had previously thought and is in the running to get this done in the foreseeable future. Peggy Funk added that New Jersey is in the same situation. They just passed some legislation, but they have no money to provide these actuarial services that NASHP is providing to the states like Maryland that received the grant. Thus, Maryland is very fortunate to be participating in this grant.

Marian Grant said that Maryland benefits from not being one of the first states and thus can learn from what other states have done. She now knows that simply passing a bill saying there ought to be a Medicaid palliative care benefit is insufficient to fund this project. So, the NASHP grant is critical to provide the analytic support and data necessary to persuade those who will fund the benefit from within Maryland. Christopher Kearney asked who is working under the NASHP grant with Peggy Funk and Marian Grant from Maryland. Marian Grant said that Ben Steffen of the Maryland Health Care Commission and Tricia Roddy of the Maryland Medicaid program were also in the group.

In Google Chat, Sarah Oliveira said “Part of the problem I’m seeing locally is that the health care system has suffered over the last couple of years and so cost savings hasn’t been the priority and instead the shift has been profitable programs. Our home-based palliative program was discontinued the beginning of this year unfortunately.”

Christopher Kearney asked if the project with NASHP will last two years. Marian Grant confirmed that was correct and said they have a work plan that goes through 2024. Christopher Kearney said that he listened to a webinar that NASHP presented and said that he learned that Hawaii has been out in front on this topic, and they were saying that CMS has recommended to them that the funding would go to preventive services, which he thought was an interesting concept. He thinks that palliative care is in many ways a preventive service. Marian Grant said this is a very significant strategic direction because there is funding for preventive services. The question then is how you align that with palliative care in that it prevents unwanted or unnecessary utilization of hospital days or however you want to articulate it, and there might be interest in depending on which route is chosen to seek a Medicaid benefit to designate it as a preventive service. Apparently, in Hawaii they could do that without having to make other changes and they just have to get approval to include it in their state Medicaid plan.

Another challenge Marian Grant talked about is which program is getting the benefits of the savings, for example, social services that save money from ended up being used in the Medicare program for unwanted treatment as opposed to the Medicaid program. She said there has lately been progress on the federal level to recognize that it is a fluid situation. So, if you have services that combine savings of social services costs or medical costs, the program should

get credit for those savings. The federal government is looking at this issue and hopefully can make some progress.

Kathy Ware said the idea of bundled payment under the preventative care model is also problematic. She had the experience of being on a multidisciplinary team and they were trying to bill for multiple services. So, the services she was providing, for example, for wound care, were getting bundled up underneath a 90-day follow-up for a surgical procedure. Although this example is not related to palliative care, she thinks that is going to be important in terms of seeing how they manage this in the Hawaii program. Marian Grant said they are figuring all that out, which lessons Maryland can benefit from. Christopher Kearney said California has also been out in front on this issue and wondered if the NASHP group had heard much from them. Marian Grant said California's program is up and running. They did it legislatively and it is a different route, and she is not sure. She said there were pros and cons to this route and that she is not sure it is the only route to get to the desired goal of establishing a palliative care benefit. She said that other routes are also valid.

Marian Grant gave an update regarding the end-of-life care in prisons workgroup. She is not sure what is going on at the Department of Public Safety and Correctional Services regarding their contract with a health care provider to provide health care services to their prisoners. Traditionally, they contract with a for-profit health care provider. The health care provider that has the contract through the end of 2023 had internal financial problems and rebranded themselves. The Department will be sending out a Request for Proposals (RFP) to obtain a bid from a health care provider to provide these services under a new contract but has not yet sent out the RFP. This RFP was scheduled to be issued on September 22, 2023. She was concerned about how a whole new health care program across the State prison system and local county jails that can provide quality care could be up and running by January 1, 2024. She has not seen the RFP because it had not been issued yet. The RFP is important because the previous contract insufficiently addressed health care for serious illness or end-of-life care. What they learned is what is in the contract is the same as what is in the RFP. So, the State can't hold the contractor responsible for something that was not in the RFP. Thus, the workgroup focused a lot on giving input to the Department regarding what should go into the RFP such as including quality measures, a definition of palliative care, and who delivers palliative care. The workgroup is hopeful that more of these terms will be defined in the RFP, but she does not know what is in it. Whatever is in the RFP, whether it is clear or not, or whether it is insufficient will be what is in the contract and will have to be lived with for another 5 years because that is the process. The workgroup tried to engage the Department in advance of their issuance of the RFP, but she does not know whether their advocacy was successful. They continue to be persistent in trying to contact Department staff regarding the RFP.

Regarding the next legislative session, Marian Grant said there will probably be bills on geriatric and medical parole that Lila Meadows of the University of Maryland School of Law is working on, and the workgroup will keep their eyes on these bills and make recommendations to the Council regarding whether to support them or not.

Jane Markley said she was appalled at how the system does not work effectively to address these problems with care in the prison system. She agreed with Marian Grant that if a

service is not mentioned in the RFP, it is not going to be provided. She appreciated the efforts Marian Grant had made. She asked if Marian Grant and the workgroup have been at all involved in the Prison Hospice Project. Marian Grant said they have talked with them. She said the issue with the Prison Hospice Project is getting people in the Department of Public Safety and Corrections to be interested in the Prison Hospice Project. She did say that their medical director they met with, Dr. Oscar Jerkins, is interested but he has a bigger issue to deal with because in the Maryland prison system there are no opportunities for custodial care at all. These facilities are not even ADA compliant. So, if an incarcerated individual is in a wheelchair and needs assistance with toileting or with dressing, the individual is just in a cell like any other incarcerated individual. He is trying to get beds set aside in a couple of facilities so that at least he can have people there who need custodial care. And then his thought was that if they have those beds, then maybe they could provide end-of-life care there. The new administration is still trying to figure out what is going on. The workgroup continues to talk with them about all of their concerns.

Jane Markley put information into Google Chat about an international doula association that is going to talk about this issue in a webinar on September 27th. [A webinar on the Humane Prison Hospice Project [umanepisonhospiceproject.org](https://inelda.memberclicks.net/septemberwebinar2023#!/Incarcerated%20and%20Dying) to be held September 27th at this link: [https://inelda.memberclicks.net/septemberwebinar2023#!/Incarcerated and Dying.](https://inelda.memberclicks.net/septemberwebinar2023#!/Incarcerated%20and%20Dying)]

Jeff Zucker said it is frustrating because the Council had so much momentum on this issue earlier in the year. He wondered if Lila Meadows had any inside information as to what was happening with the contract or whether there was any talk of an extension. Marian Grant said Lila Meadows is not engaged in that process at all. She said Lila Meadows does the advocacy on the release side of the prison issue, so she is less knowledgeable about the RFP. Marian Grant thought that an extension was a possibility but can't get anyone to respond to her. She said that earlier in the year it was a new administration who did not know about the Council and thought they needed to talk with the Council. And then real life intruded and they figured out all the things that they had to do. Maryland had a budget surplus and now it does not. So, these are tricky times financially and they are probably lean in staffing and unlikely to get less lean. So, she thinks it is just an alignment of things out of the Council's control. The workgroup has continued to reach out to the Department, but it is out of their hands at this point. Jeff Zucker wondered whether the Council should ask Senator Ben Kramer or Delegate Bonnie Cullison to come back in and just send a letter and ask for an update from the Department because the contract is expiring. Marian Grant agreed that the Council could send a letter to the Department. Christopher Kearney agreed and said that was a good idea. He complimented Marian Grant for her work on this project.

Christopher Kearney said the incarcerated elderly are a growing segment of the Maryland population every year and everywhere else and he thought that it is the Council's business to be involved in this issue. He spoke with Lila Meadows, and she told him she is not getting any information either except that there is not enough oxygen available now in the prison health system. So, this issue is not going anyway any time soon and the problem grows.

Jeff Zucker said that we know this issue will come back to the forefront when there is a headline of an incarcerated patient that's not treated well. And those incidents tend to turn into lawsuits. The existing contract did not ask for the number of advance care planning documents, that they be accessible, that they are being used, and that it doesn't take much for this to the lack of this information to become an issue. Perhaps the Council could remind them of the Council's work and that clarification of the contract would help the Department rather than creating more work for them. Marian Grant agreed that was a great suggestion and she thought the Council could send a letter to the Secretary of Public Safety and Corrections to follow up, to say we met with your team and could you give us an update. Jeff Zucker suggested cc'ing Ben Kramer and Bonnie Cullison. And Marian Grant suggested cc'ing Secretary Scott of the Department of Health and Secretary Roques of the Department of Aging. Christopher Kearney agreed. Marian Grant asked Paul Ballard to draft a letter.

Kathy Ware talked about messaging to get the Governor's attention. She said that the Governor's priority is veterans and the armed forces. She asked if anyone knew how many veterans are incarcerated. Marian Grant said that people lose their Veterans Administration, Medicare, and Medicaid benefits when they are incarcerated. Jeff Zucker said the Council could do a point of inquiry on the Veteran's Administration side to see how many veterans they dropped from their benefits due to incarceration. Kathy Ware said she would try to find that information. Christopher Kearney said there is a Veterans' clinic at the University of Baltimore Law School that is involved pretty heavily in veterans' affairs, though he was not sure how much they know about their incarcerated veterans and their care. But he will look and see if he can find out any information. Kathy Ware said there are veterans' advocacy groups that may be a source of information. Marian Grant said that concentrating on incarcerated veterans might be another basis to advocate for compassionate release or medical or geriatric parole. She said that politicians don't want to let bad people out of prison but if these people are also veterans, you might be able to garner a little bit more support. Kathy Ware thought that maybe Lila Meadows knew something about it too and she would be happy to reach out to her about that potential argument. Marian Grant said it might have been an angle they previously explored, and perhaps it wasn't productive, but she did not know. Kathy Ware said she knows someone through Wounded Warriors that works with amputees, and she could try to go through Wounded Warriors also. Christopher Kearney asked if Kathy Ware would include him in that effort to find out more information and she agreed to do so.

Jeff Zucker suggested that the Council urge the Department of Public Safety and Correctional Services to consider an extension of the existing contract before they sign another multiyear contract that is so utterly flawed. Marian Grant said she would try to reach out to their procurement staff person. Christopher Kearney and Marian Grant said the Council would draft a letter to the Department of Public Safety and Correctional Services containing a query with copies to Senator Ben Kramer, the Department of Health, and the Department of Aging, to say the Council is still interested in the project and whether there is anything more that the Council could do to be helpful at this time. Paul Ballard confirmed that the letter would be to ask for an update regarding the Council's prior queries. Marian Grant asked that the letter include questions regarding what the status of the RFP is, when will it be issued, and whether there is going to be enough time or whether they can ask for a contract extension. Paul Ballard said he would be in

touch regarding the letter. Peggy Funk thought that it would be good to also cc Delegate Pena-Melnyk, because she is Chair of the Health and Government Operations Committee. This would be a cause that she would be very interested in.

Marian Grant said a New York Times article stated that former president Jimmy Carter, stopped treatments and had gotten hospice, that he hasn't seen a doctor in seven months, that they don't know why he is still alive, and that his family doesn't know why he is in hospice. She emailed the Times reporter to say that the Times continues to be inaccurate in reporting that hospice care is not medical treatment. She noted that hospice care is paid for by insurance companies that only pay for medical treatment. She also wrote that although Jimmy Carter has not seen a doctor, he has seen a hospice care team regularly. She noted that people who receive hospice care actually live longer, and that Jimmy Carter has metastatic cancer and that is probably a terminal diagnosis. She wrote that if other people with metastatic cancer knew that could have this good an outcome, maybe they would choose hospice care too. She will also write a letter to the editor because is the third or fourth inaccurate article in this regard that mischaracterizes hospice care as stopping medical treatment.

Peggy Funk said the Hospice and Palliative Care Network of Maryland Annual Conference would happen on October 19, 2023, at the Maritime Conference Center in Linthicum.

Scott Brown said that AdVault (MyDirectives) and Aging with Dignity (5 wishes) have formed a very close collaboration. This gives Aging with Dignity a viable technology partner in AdVault. AdVault will be integrating the 5 Wishes advance directive document, their resources, and everything they have into both AdVault's consumer-facing platform (MyDirectives) and their clinician-facing tools (MyDirectives for Clinicians) (MyDirectives and Five Wishes Press Release Announcing Collaboration:

<https://www.businesswire.com/news/home/20230920733782/en/Five-Wishes%C2%AE-and-MyDirectives%C2%AE->). Christopher Kearney thought it was well timed to form that alliance.

Marian Grant talked about a 5 Wishes experience she had at the University of Maryland Medical Center where she is a palliative care nurse practitioner. She was taking care of a patient in the shock trauma area where they rarely call the palliative care team. She was called because the health care providers wanted to talk with the patient and the family about goals of care for a patient who was Bengali but only some of the family was there. So, she went back to her office and her colleague informed her they had a copy of the 5 Wishes form in the Bengali language. And the health care providers were very appreciative when she brought back the form in Bengali. So, she said if 5 Wishes could have an online version in Bengali, that would be amazing. Scott Brown said they are working on that and also are digitizing 5 Wishes' Voicing My Choices for pediatric and adolescent care. So, they are working on lots of great initiatives together with 5 Wishes.

Tammy Turner is working on creating a nonprofit called Care Prepared that does outreach and education and documentation for advance care planning and the MOLST form. She asked whether the MOLST form was necessary if a patient does not want CPR administered. Paul Ballard said that was correct and he said they will also accept out-of-state EMS DNR order forms too. EMS may modify the out-of-state form's order to fit the MIEMSS protocols. He noted

that health care providers are also required to comply with out-of-state EMS DNR order forms and out-of-state advance directives. He stated that a nursing home that admits a patient with such an out-of-state order form must comply with that out-of-state form pending their completion of a replacement Maryland MOLST form. Tammy Turner asked whether the MOLST form had to be a paper document and what the EMS crew looks for. Paul Ballard said that ideally if someone were in the home with the patient, they should hand the form to the EMS crew. Otherwise, EMS is going to look for the form on the refrigerator door, by the patient's bedside, and behind the patient's bedroom door. He explained that MIEMSS wants people to have paper MOLST forms available to give to EMS because not every EMS provider has the ability to deal with electronic MOLST forms. Ultimately, it would be ideal to have one electronic source of the MOLST form.

Scott Brown said that MedStar uploaded more than 2000 Maryland MOLST forms to their EHR system every month. They are working to expose those forms to CRISP. They had talked to some of the EMS providers about their electronic platform called the EPCR. He said ImageTrend is a very large company with a large influence in the EMS market in Maryland. AdVault has spoken with ImageTrend and AdVault would appreciate any support they could get from actors in the State to push that integration along because EMS does not always look for those documents that are available on CRISP. AdVault has also built out the D.C. MOST form in their library for their clinician-facing tool. They are also working with national POLST to get their guidelines and best practices in context in the creation of those documents to assist people who are providing advance care planning. So, those documents are in AdVault's system, they are available to be created using their tools, and they fully support the effort and are available to help. Paul Ballard clarified that electronic versions of the Maryland MOLST form are valid, and it is only the practical considerations that prevent EMS from using them more. Jane Markley noted that EMTs are really good in that one will go to the patient, and one will go to the refrigerator to check for a MOLST form. Scott Brown agreed that the electronic MOLST forms exist, they are valid, and that AdVault just needs help seeding the system to increase their use.

Tammy Turner said that she has found in her research that not a lot of health care providers take the time to explain to people the importance of the MOLST form when you have a serious illness, and then actually document it unless the patient is in a palliative care program. A lot of other people could benefit from understanding those forms. She wants to create a bridge for that gap with her nonprofit. Christopher Kearney applauded her efforts and said from his years of experience that it is difficult to get a MOLST form that was seriously and thoroughly considered when it was created. Often, the consideration given to the MOLST form is pretty brief. So, a lot of work is needed to get them more seriously considered when they are created.

Cathy Pauley returned to the issue of prisoner rights. She said they had a patient in the ICU at GBMC that came from the Baltimore County detention center and that medical decisions needed to be made for this patient. They had reached out to the detention center to gather information about next of kin but the detention center refused to give them any information and said their doctors were the decision maker for this nonviolent offender that was in the ICU. So, she thinks there is a need for education regarding prisoners' rights regarding health care decision making. Even a prisoner has the ability to name a health care agent and have representation in that area. She was ultimately able to get a health care agent for the prisoner who named his brother as his agent. Christopher Kearney said a prisoner may be seriously ill in the hospital for

many weeks and no one in the family would ever know they were in the hospital. Often, prison officials don't want anyone to know that a prisoner has been moved. He suggested that Cathy Pauley might wish to contact Lila Meadows about the issue. Cathy Pauley said it was very frustrating dealing with the prison's view that the prisoner had no right to appoint a health care agent. Christopher Kearney told about his trip to a prison with Lila Meadows. He said he was stunned to meet a prisoner there who had been hospitalized for almost a month and his family had no idea he was in there the whole time and near his death.

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