

State Advisory Council on Quality Care at the End of Life

Minutes from the January 29, 2024 Meeting

Meeting time and place: January 29, 2024, 10:00 a.m., via video conference.

Council members present: Christopher Kearney; Paul Ballard (Attorney General's designee) (in-person); Jane Markley; Peggy Funk; Gail Mansell; Donald D'Aquila; Shahid Aziz; Delegate Ashanti Martinez; Sara Hufstader; Elena Sallitto; Stevanne Ellis (Department of Aging's designee); Steve Glazer; Tiffany Callender Erbeling; Nicole Lopez de Victoria.

Others present: Dan Morhaim; Jeff Zucker; Kathrine Ware; Stacy Howes; Brian Mattingly; Sadie Peters; Donna Amelio; Jackie Ogg; Joanne Ogaitis; Kathrine Ware; Laura Jones; Liz McDonell; Marian Grant; Michael Munoz; Debbie Ahl; Pat Alt; Anita Tarzian (via AI assistant taking notes).

Chairman Christopher Kearney opened the meeting. The November 9, 2023 minutes were approved.

Christopher Kearney talked about the passing of Steve Levenson who had served on the Council for many years and was a very active participant in health care in the State of Maryland for years. He was the medical director at Levindale Hebrew Geriatric Center and Hospital and was the regional medical director for Genesis Healthcare. He also most recently worked for the Maryland Office of Health Care Quality. He had written books on long term care and many articles in professional journals. He was president of the Maryland Medical Directors Association, he was very involved in the area of healthcare decision-making, with the interpretation of the Maryland Health Care Decisions Act, the creation of the Maryland MOLST form, and the creation of patient advisory committees in hospitals and nursing homes regarding ethical issues. He left a huge legacy helping healthcare in Maryland in many different ways. Gail Mansell remembered Steve Levinson as being a phenomenal educator.

Delegate Ashanti Martinez talked about House Bill 461, which he introduced to change the Council's name to the State Advisory Council on Serious Illness Care. He told the Council that the hearing on the bill would be held on February 7, 2024. He will let people know how they can testify in support of the bill if they want to be part of the panel to explain why the change of the name is so vital to the work of the Council, especially in educating people about the work that the Council does. He has asked a Senator to cross-file the bill but believes that cross-filing won't be necessary because it is such a simple bill that only changes the name of the Council.

Christopher Kearney asked Delegate Ashanti whether he was aware of any legislation that the Council should be apprised of. Delegate Ashanti talked about a bill regarding how health care workers are paid and a bill to provide reimbursement for those who are taking care of loved ones at home but said he hasn't seen a bill directly related to serious illness care or palliative care. He did say that the End-of-Life Option Act bill was introduced by Delegate Terri Hill and that he is a cosponsor. Christopher Kearney noted that the Council is aware of the End-of-Life Option Act bill but has determined that it has nothing to add to the discussion but would always be advocating strongly for hospice care or palliative care for all people who are seriously ill. Delegate Martinez said that the bill is about providing options and that he and all the cosponsors

want people to have the ability to make choices, which allows them to determine the outcomes of their healthcare, which is so important for those people dealing with a serious illness who so often don't have things under their control. Enactment of the End-of Life Option Act would allow them to be able to have an option to choose the outcome that they would like. But he understands why the Council might want to take a neutral position because of the work that it does. He was glad to get the Council's name change bill filed early because that increases its chance of passage during a short legislative session.

Christopher Kearney noted that Brian Mattingly and Dr. Sadie Peters from the Maryland Department of Health were in attendance. At the last meeting, the Council became aware of the Maryland Cancer Collaborative's active work in advance care planning. Given the Council's long interest in promoting advance care planning, the Council thought it might be worth exploring working in partnership with the Cancer Collaborative. Christopher Kearney and Paul Ballard talked with Brian Mattingly and Sadie Peters about their work and invited them to attend the Council's meeting.

Brian Mattingly gave a brief update to the Council and will give a more detailed update at the next meeting. He said he is the director of Maryland Comprehensive Cancer Control Program. They put out the State cancer plan every 5 years. They support the Maryland Cancer Collaborative and one of the strategies of the cancer plan is related to advance care planning. They formed a workgroup to develop a project to increase the creation and updating of advance directives by cancer survivors. They are working with Luminous Health's cancer services line which is going to be utilizing MyDirectives.com for clinicians to support cancer survivors to create and update cancer plans.

Sadie Peters said she is an internist physician who recently became the medical director for the Cancer center at the Maryland Department of Health. She has been picking up on the Department's past efforts on advance directives and community education and outreach that has been going on for a few years, which she is trying to resurrect that thread of the work that the Department does. She is trying to revive the work the Department did across the State with various community organization across the State in 2017, 2018, and 2019, trying to educate the public about advance directives in general and also pushing the idea of electronic advance directives to improve their accessibility when needed. They have plans to reach out to community organizations which they have already worked with and also to hear from more people than those that the Department has worked with in the past to understand what the needs are. Covid really highlighted the needs of a lot of advance care planning in ways that they had not thought of when they first started doing this work in 2017. The conversations are just starting for this new community education and outreach, so that hopefully at the next Council meeting they will have more concrete plans and strategies to share with the Council. And she and Brian will reach out to the Council regarding things that the Council may want to do to help the Department in this effort.

Jane Markley said she was thrilled that Brian Mattingly and Sadie Peters were working on promoting the use of advance directives. She expressed the hope that they could help the Council with National Healthcare Decisions Day in April and asked if they had anything planned for that event. The more information they can get out to the community about that event, the

more visibility they are going to have for advance directives. She mentioned Dan Morhaim's efforts to promote National Healthcare Decisions Day and that in his time as a Delegate he had sponsored a bill that was passed requiring the Governor to recognize National Healthcare Decisions Day. Sadie Peters said she is looking forward to collaborating with the Council and Dan Morhaim.

Jeff Zucker expressed his concern that the proposed change of the Council's might give the mistaken impression to the public that advance directives are meant only for seriously ill people even though every adult needs to prepare an advance directive. Christopher Kearney agreed that this was an important point. Brian Mattingly agreed that everyone should complete an advance directive. He noted that Dan Morhaim would be speaking about advance directives at the Johns Hopkins Community Health Call, which call has been held every week since the pandemic to inform community leaders about health-related topics. Hopefully, people can be encouraged to complete advance directives when they are healthy and when they are young.

Christopher Kearney thanked Peggy Funk and Marian Grant for drafting the Council's letter to the legislature in support of the Maryland Health Care Commission's Palliative Care Workgroup Report. Peggy Funk said the report went to the legislature in November, 2023. The purpose of the report was to let the legislature and the Governor know that the Council supports the idea of palliative care in Maryland and supports the Workgroup's recommendations in the report. The Council's letter went to two very important legislators, Senator Pamela Beidle, Chair of the Senate Finance Committee, and Delegate Joseline Pena-Melnyk, Chair of the House Health and Government Operations Committee. The Hospice and Palliative Care Network of Maryland sent in a letter to them as well to thank Delegate Ken Kerr for sponsoring the legislation creating the workgroup and to let them know the Network is also working with the Council. The hope is to keep the report's recommendations in the forefront. She thanked Marian Grant for her great help with the letter. Peggy Funk also talked about the possibility of forming a workgroup to try to monitor and follow up on Palliative Care Workgroup's recommendations in hopes of getting them implemented.

Christopher Kearney asked how these recommendations get tracked. Peggy Funk said it is really up to the Council and others to track them. The Network will be talking to a lot of their representatives about the recommendations. A lot of the tasks will fall under the National Academy for State Health Policy (NASHP) Grant's workgroup. Christopher Kearney noted that Maryland is one of 6 states working under the NASHP grant investigating financing for palliative care in their individual states. The members of the Maryland workgroup are Peggy Funk, Marian Grant, Ben Steffen of the Maryland Health Care Commission, and Tricia Roddy of the Maryland Department of Health's Medicaid Program.

Peggy Funk said the grant is the serious illness institute which is a two-year program and that they have completed about a year to this point. The group has not met since November, 2023. The next step is that the NASHP group is trying to collect some data because the next step is that Maryland workgroup members are trying to figure out if a benefit was created, how much it would cost to cover these individuals, and what type of health care professionals would serve on the palliative care teams taking care of seriously ill patients.

Marian Grant said the benefit of the grant is they get the benefit of free analytical work provided by the grantor. The meeting to talk about the data was scheduled to occur in February, 2024, if the data can be gathered and analyzed by that time. The savings that would come from a Medicaid palliative care benefit in Maryland is a key piece of information needed to convince people to create such a benefit. Other states that have created such a benefit have had a serious illness coalition, a palliative care coalition, or some kind of structure where it is included in their ongoing work on Medicaid expansion. Maryland is going to need such a coalition to get this done. She hopes that the creation of such a coalition and changing the name of the Council to emphasize serious illness care will help it to promote the creation of a palliative care benefit. She asked for volunteers and for people to think of potential partners for such a coalition to be sure there is sufficient stakeholder support.

Christopher Kearney asked for ideas about who potential supportive stakeholders might be. Some of the people that have come to mind are the Maryland Secretaries of Health and Aging. He said the Council would be meeting with the Secretary Roques of the Department of Aging in February, 2024, to update her about the Council's activities in general and he hopes to have more specific information regarding the Council's efforts regarding any palliative care benefit the Council might be advocating for. He is also in the process of scheduling a meeting to update Maryland Department of Health Secretary Scott who is very familiar with palliative care and the financing of palliative care.

Marian Grant said the Council must get people from the community to support the Medicaid benefit in addition to the State's departments such as the Maryland Hospital Association, all the key health systems that have palliative care, organizations in the community that are offering palliative care, the disease advocacy community such as the Cancer Society, the Heart Association, dementia advocacy groups, and other organizations, including the aging community. Many of the advance care planning groups may be interested because advance care planning is one way to facilitate advance care planning on an individual patient basis. Peggy Funk said post-acute care organizations should be recruited too, such as LifeSpan Network, HFAM, and Maryland adults with disabilities organizations. She thought a lot of those organizations could be very helpful. Marian Grant said these conversations need to take place in the next few months so that these organizations are made aware of this effort in advance of any concrete proposals being made. It will be challenging for the Council as a volunteer organization without a full-time executive director.

Jackie Ogg, who coordinates the Montgomery County Palliative Care and End of Life Coalition, said to consider the social determinants of health, including housing, work force and the faith community, who are ready made partners in Montgomery County that the Council could contact. Kathrine Ware also said she is on a committee of the nurse practitioners' association and asked if they would be a helpful partner in this effort. Peggy Funk suggested that a fact sheet be created to give to Kathrine and others. Marian Grant said she could try to do that.

Christopher Kearney said the project regarding creating a palliative care benefit may be one of the most important efforts undertaken by the Council to improve serious illness care. Marian Grant confirmed this would be a multi-year project. Marian Grant thought this would

need to be a standing agenda item for the Council for the foreseeable future and Christopher Kearney agreed.

Christopher Kearney initiated the discussion of the issue regarding the care of incarcerated seriously ill Marylanders. Marian Grant said the care provided in Maryland is contracted out to a for-profit organization and the contract is ending. The Council was not able to influence the contents of the request for proposals (RFP) for the new contract. The current contract has been extended through March 1, 2024, while the Department of Public Safety and Corrections is reviewing proposals submitted in response to the RFP. They did get multiple proposals. Unfortunately, the contract will just include whatever was in the RFP.

Marian Grant said that the Council had supported several bills in the 2023 legislative session regarding medical compassionate and geriatric release and she has not followed those bills this session because their contact, who is a professor at the University of Maryland School of Law, is out on maternity leave. Marian Grant said she was disappointed that that none of the bills the Council supported in 2023 were successful, probably because politicians want to look tough on crime.

Christopher Kearney said he is a little less discouraged by the RFP process because the medical director at the prisons is very concerned about the quality of serious illness and end of life care there and was receptive to the Council's suggestions. He agreed with Marian Grant that there is not much chance of the compassionate release bills passing. He hoped that Lila Meadows, the law professor, would be back to work soon and could update the Council again.

Paul Ballard said he had not seen any legislation that is significant to the work of the Council other than the bill Delegate Ashanti has introduced to change the name of the Council and the aid in dying bill that the Council is not taking a position on.

Laura Jones said her organization is called the Dignity Mandate and they have been following the End-Life-Option Act for several years, which bill they oppose. She offered the Council information on palliative care and hospice care diminishing in states where bills like these have been enacted into law. She said she had factual information to offer about the drugs they use as not being effective or safe. She said she was trying to get the information to Peggy Funk. Peggy Funk then gave Laura Jones her email address. Christopher Kearney asked Laura Jones to send the information to Paul Ballard who would be able to distribute it. Christopher asked whether the End-of-Life Option bill is any different this legislation session from past sessions when it has been introduced. Laura Jones confirmed that it is the same bill. Christopher Kearney thinks it looks very much like the laws passed in other states and the District of Columbia where aid in dying is permitted. In his field of palliative care, he has been strongly in favor of better palliative care while staying neutral about aid in dying legislation. But he would be interested to see the information she offered. Paul Ballard offered to distribute whatever Laura Jones would provide to him.

Marian Grant wondered whether aid in dying is in practice an option now in Washington, D.C. even though it is now legally authorized there. Jane Markley said she heard that they were having trouble getting the right pharmaceuticals to be available and the pharmacies being willing to sell them. Laura Jones said the drugs they use in Oregon for this purpose are not FDA

approved and they also change every year. So, it puts pharmacies in the position where they are trying to come up with a concoction that is not very well vetted. She said the drugs are based on the Oregon report because it is the State that has had the law in place for the longest period of time, 25 years. She has this and other reports available for the Council's review.

Don D'Aquila said that the drugs historically used for this indication are no longer available or are very expensive. The pharmacies that are doing this are all specialty compounding of medications, so it is very complicated. Christopher Kearney noted Don D'Aquila's is one of the more important palliative care pharmacists in the State of Maryland in his opinion, so that he has a lot of experience. Christopher Kearney is certain that pharmacists are concerned about this topic generally as being very complex for them as well.

Peggy Funk said that the Hospice and Palliative Care Network of Maryland has monitored the aid in dying bill for over the past 8 years and they do take a neutral position. But they offer a letter of information to legislators each year that talks about all of the options. Christopher Kearney noted that most of the people who were applying for aid in dying in Oregon and the State of Washington were already in hospice care. That assured some people in the palliative care field that by being in hospice care they were getting good end-of-life care.

Dan Morhaim trusted that the Council would have written testimony or in-person testimony for House Bill 461. And he said that letters from individuals are good. Christopher Kearney agreed that would be a good idea. He also suggested that Delegate Martinez contact Senator Kramer about the bill too. The Council agreed to send a letter of support for House Bill 461. The Council would find someone to testify too. Kathrine Ware will write a letter of support as an individual.

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