

State Advisory Council on Quality Care at the End of Life
Minutes from the October 26, 2018 Meeting

Meeting time and place: October 26, 2018, 10:00 a.m., Office of Health Care Quality, 55 Wade Avenue, Spring Grove Hospital Center, Bland Bryant Building, Catonsville, Maryland.

Council members present: Alan Eason, Chair; Paul Ballard (Attorney General's designee); Stevanne Ellis (Department of Aging's designee); M. Jane Markley; Rabbi Steve Glazer; Tiffany Callender; Delegate Dan Morhaim; Carol Eckerl; Christine Watts; Sister Lawrence Mary Pocock; Christopher Kearney. On speakerphone: Hank Willner; Elena S. Boisvert; Gail Amalia Katz; Marian Grant; Michele Williams.

Others present: Frederick Weinstein; Peggy Funk; Carol Cronin; Phyllis Gray.
On speakerphone: Christine Boyd.

Chairman Alan Eason convened the meeting at 10 am.

Christine Boyd, Health Policy Analyst with the Maryland Department of Health's Prevention and Health Promotion Administration, gave an update regarding the Department's Advance Directive Education and Outreach Program. She stated that her program is devoted to education and outreach regarding the promotion of advance directives, including introducing the concept of preparing electronic advance directives, especially through a vendor vetted and recognized by the Maryland Health Care Commission (MHCC) to create advance directives that are electronically accessible to providers through the Chesapeake Regional Information System for our Patients (CRISP), a cloud-based electronic medical records system in Maryland hospitals. Beginning in July, 2018, MyDirectives.com became the first and currently only State recognized electronic advance directives vendor connected to CRISP. MyDirectives had previously engaged in a pilot program with MHCC and CRISP.

Christine Boyd said that the Department's advance directive education and outreach program has engaged in a 1-year long period of outreach with 13 partners and that the Department's grants sponsored approximately 100 events. She stated there were more than 3,000 participants and over 2,100 surveys were collected. She said there are about 14 questions on the survey, including asking who the participants are, whether they had already prepared advance directives, some of the reasons they may or may not have advance directives, and some of the messaging that may help to change their behaviors and attitudes towards advance directives. Consistent with the literature regarding advance directive completion, about one third of the participants already had advance directives and about 85% of attendees after attending an event intended to create or update their advance directives. She said the sessions are effective in generating conversations and changing attitudes towards creating or updating an advance directive.

Christine Boyd said that about 70 to 75% of attendees are women and thus the program will be trying to get more men to participate. She stated that program is also asking attendees to tell 2 or 3 people about what they learned at the session, to invite others from their book club, garden group, or whatever the group might be, to come and participate in an education session. The grants will run through end of March, 2019, at which point the program will have gathered a

huge amount of data that will be synthesized and pulled together into a comprehensive public paper. The program has a summary of the pilot program that was completed about a year earlier with similar engagement activities as outreach in the faith-based community. She said that the program will have a short white paper containing that summary that they will be able to share very soon with the Council.

Jane Markley asked whether a person may upload a paper-based advance directive onto MyDirectives.com. Christine Boyd replied that a paper-based directive may be scanned and uploaded onto MyDirectives.com. Christine Boyd said that a person completing the advance directive can do it at their leisure at home on their own time. MyDirectives is comprehensive, walks the person through the steps of creating a health care agent and stating their wishes, and asks detailed questions if the person wants to specify additional wishes. She said it is a free service and is user friendly.

Tiffany Callender asked if MyDirectives is working on making its paper upload process easier for the user. Christine Boyd replied that MyDirectives is constantly doing upgrades and said the MHCC would better know about those efforts. Tiffany Callender asked what message-wide coordination existed among grantees regarding the type of events, messaging and outreach. She also asked what was planned after the grants run out in March, 2019. Christine Boyd replied that the program was overwhelmed by the responses by applicants for grants and awarded 13 grants. She said that the program has tried to unify the messaging and provide a framework for grantees but decided to let the grant applicants decide on marketing efforts because they have more expertise in what appeals to their groups. The grantees promoted advance directives through a variety of ways, including movies and plays. She said the goal is to give information rather than to create advance directives at an event. She also said that there is a handout that the Department offers. The program is working on budgets and funding to continue beyond March, 2019.

Dan Morhaim thanked Christine Boyd for her work. He said he has a MyDirectives ID Code that can be used outside of Maryland and that prints out on MyDirectives. He asked if there were plans for the CRISP site to have a separate tab that says advance directives. Christine Boyd responded that she did not know but that she knew that CRISP is pushing for a method where the data is pushed automatically so that clinicians do not have to search for the advance directive. Dan Morhaim said that advance directives need to be in same place so as not to require the clinician to hunt for where the advance directives are located.

Christine Boyd said that education to physicians that advance directives are on CRISP is being discussed as another topic for future funding. She also stated that people at the engagement activities have asked what would happen to their electronic advance directive if something should happen to them while they are in a different state other than Maryland.

Dan Morhaim said that one-third of people have advance directives and this percentage is even less among minority groups and asked how the Department's program was reaching out to minority groups that have had a historical mistrust of the health care community. Christine Boyd replied that the grantees' groups are already motivated to complete advance directives. She said that in terms of reaching minority groups they have done a lot of outreach to faith-based communities, including Muslim, African American and Asian American communities. She said

that by March, 2019, the Department hopes to have a lot of information to share regarding what's working with different groups. Dan Morhaim mentioned that it would be helpful to have a real celebrity promote advance directives. Christine Boyd agreed and said that the Department put out a Request for Proposals (RFP) for a 5-year media campaign that had recently closed, and she hoped that a celebrity Public Service Announcement may result from this RFP.

Attending his final meeting as a Council member, Dan Morhaim thanked the Council, Ted Meyerson (the previous chairman of the Council), Paul Ballard and Tricia Nay for all their work with him on his successful legislation such as the MOLST law, electronic advance directives, National Health Care Decisions Day and other legislation related to end-of-life issues. Paul Ballard praised Dan Morhaim's legislative legacy.

The Council members introduced themselves, including first time attendee Christine Watts, a nurse case manager at Medstar Family Choice. She manages a lot of catastrophic cases with end-of-life needs and has worked as nurse for many years in many venues, including in research, in the ER, as an adjunct professor at Morgan and Towson, and as a hospice nurse. She said she is still working as a nurse in Patient First at Owings Mills. Alan Eason asked her if there is any big issue from her perspective regarding end-of-life care. She stated that we need to have more discussions regarding palliative care, as well as about hospice care. Mostly, she said that palliative care needs to be promoted in the medical community.

Christopher Kearney and Marian Grant gave a PowerPoint presentation regarding palliative care. Marian Grant stated that it is an exciting time for improving care for patients with serious illnesses. She said that Medicare Advantage is now offering supplemental benefits. She also said there are demonstration projects with encouraging results. Approximately 20 health plans across the nation have decided to do this and that there are lots of State and local projects. She said there is a huge opportunity to improve care. She said that patients go to the emergency room and end up in a merry-go-round between a hospital and home and don't spend enough time at home, which is not what they want. Christopher Kearney stated that one half of the patients they have should not be in the hospital for care if we had a decent health care system. Marian Grant said it would be ideal for the home to be the center of care for a person with serious illness instead of the health care silos and conveyor belts of the current health care system. She envisioned care as an ecosystem where care is integrated into all aspects of the community and not separated from the rest of people's lives. States doing this have similar groups involved. She said the various states' palliative care coalitions vary depending on why they were formed and who is funding them. She said that California has the most well-established coalition and is focused on advance care planning, POLST, education, public policy, palliative care, and that this coalition convenes a summit.

Christopher Kearney said that California has done a lot of work and that Maryland shouldn't reinvent the wheel. He noted that Blue Shield in California offers palliative care as a standard insurance benefit. Marian Grant said California changed some of their regulations because they created barriers to home care. Christopher Kearney said that United States is the only place in the world that requires patients to give up curative treatments to get hospice care. He said that other countries instead have a seamless version of palliative care services. He also said that California is allowing hospice-trained workforce to provide palliative care services to patients that are not

certified with a prognosis of only 6 months to live. Phyllis Gray stated that California's coalition is looking at how many days cancer patients stay at home in the last year of life. She said that California's coalition believes that the health care system should be able to manage people better in their homes.

Peggy Funk said the Hospice and Palliative Care Network of Maryland is working closely with Blue Cross/Blue Shield CareFirst, which is currently offering this benefit. Marian Grant said that Maryland's CareFirst had a chronic illness program and was coordinating with hospice care programs but stopped that benefit. Instead, she said CareFirst is launching a new palliative care home-based pilot in Maryland. Stevanne Ellis asked whether Marian Grant has a timeline regarding California's palliative care coalition. Marian Grant replied that the coalition had a dedicated organization for the last 10 years.

Marian Grant said the Massachusetts Coalition for Serious Illness Care has existed since 2014 and is mostly about documenting wishes and care preferences and is using Atul Gawande's "Serious Illness Conversation Guide," which it is widely deploying with strong leaders and good resources. In Oregon, Cambia (i.e., Blue Cross/Blue Shield) created a coalition that is focused on palliative care and identified gaps in care. She said they are trying to bust silos and create work groups that span across organizations so that people who don't traditionally work together will begin to do so.

Christopher Kearney said South Carolina has done good work and there is no shortage of examples. Christopher Kearney said the time is ripe for this and there is a lot of interest in Maryland. He said their Maryland coalition has hooked up with the Hospice and Palliative Care Network in Maryland to work on the project. He said that everyone is talking about community centered care rather than inpatient care. Peggy Funk said that they will go further upstream to include members from all over the community that work with chronic disease and not just hospice patients. They have developed a name for the coalition, the Serious Illness Coalition of Maryland, and are developing a website and a logo. They are also looking at how to train clinicians. She further stated that they need to identify community based palliative care providers who can treat people they refer, and that they need to identify models and train providers and look at what the revenue stream would look like.

Marian Grant wanted the Council to know there is space in the coalition for persons interested in advanced care planning, etc. in addition to palliative care. Carol Cronin of the Informed Patient Institute said that her group decided to work on end of life care issues with a focus on advanced care planning, including having conversations, documenting and having wishes honored. Marian Grant said she wanted to keep the Council aware of the coalition's project and welcomed input from the Council.

Christopher Kearney said he would like the Council to be part of the Coalition. Alan Eason said he liked the idea but would like Paul Ballard to do some research on the State Advisory Council. Paul Ballard said the Council can always work with the Coalition without officially being a member. Alan Eason wanted to know what the statutory provisions regarding the Council would allow regarding the Council's participation in the Coalition. Paul Ballard said the Council could always endorse the Coalition's recommendations and work with the Coalition. Christopher

Kearney asked if the Council could endorse legislation to mandate and pay for a palliative services benefit as California did. Alan Eason said that he would first like to do a little background research and asked Paul Ballard if the Council could vote on something by email without having a meeting. Paul Ballard said the Council could send someone to the Coalition's meetings, endorse the Coalition, make recommendations, and play whatever role the Council wants to play.

Tiffany Callender said she was hesitant about the name of the Coalition because the term "serious" might deter consumers from joining because it would appear like it is only for really sick people. Dan Morhaim made the point that advance directives are not just for old people and said the more you can do without legislation the better. He said that the Council carries credibility with the legislature. He suggested that right after election the Council should announce to legislators that the Council exists and that the Council can be used as a resource. Jane Markley said that the Montgomery Palliative Care End of Life Coalition is focused on community care but was not sure whether it was working in the same direction and thus coordination is important. Dan Morhaim said that terms like "empowerment" and "your wishes" are better so that people are not deterred. He noted that there are very few things in the health care system where people can say what they want.

Phyllis Gray said care guidelines for oncology patients say that health care providers need to talk with their patients about these issues at the time of the diagnosis rather than at the end of life. Steve Glazer said that his late wife received excellent palliative care and hospice care because he knew about palliative care, requested palliative care services, and suggested a palliative care consult at the initial meeting with the oncologist. He said that education is needed for the individual at the micro level so that they are aware of these care options. Another Council member shared a personal story about a young relative who had suffered from a fall that created a traumatic injury. She said how helpful it was for all the family members, young adult children and parents alike, to have spoken about these issues that resulted in the young relative's advance directive. Indeed, the young adult children wanted to make sure that their sibling's wishes were honored and the decision was made to let her die peacefully. The council member said it was important to talk to young adults about these issues too. Dan Morhaim said that when he talks to graduate students that he assigns them to prepare an advance directive, and that he always asks lobbyists to prepare one.

Paul Ballard stated that Nichole Majewski at the MHCC told him that MyDirectives had been recognized by MHCC to connect to CRISP as an electronic advance directives vendor and that MHCC is looking at two other vendors for possible recognition. MHCC is working on enhancing integration so there are more context alerts to enhance the functionality of how to retrieve information so that providers understand how to get information and to get it quickly. He also shared with Council members what is on the MHCC's website regarding the criteria for State recognition of an electronic advance directives vendor. He said you can also see the application on the website that vendors have to complete.

Paul Ballard mentioned that he attended an ePOLST conference because it is important to think about how Maryland can develop an eMOLST program in Maryland. He said that the national POLST (Physician Orders for Life-Sustaining Treatment) organization is working on developing

a white paper that will contain national guidelines for ePOLST. He stated that some other states such as Oregon have developed good programs and that he learned it is critically important to develop a system that is both user friendly and financially sustainable over time. He talked with CRISP about developing an eMOLST program and learned that it is very important to make sure the system is populated with MOLST forms so that people know they can find them in CRISP's system. He said there are many issues with creating and sustaining an eMOLST registry. He said he liked Oregon's system which operates as a back-up system for their EMS providers.

Jane Markley said that the District of Columbia had approved a MOLST order form.

Christopher Kearney said that Medstar had added "Allow Natural Death" to its DNR (Do Not Resuscitate) order forms and in order to do so they had needed to fit the phrase into one line with DNR and DNI (Do Not Intubate). Hank Willner said he wanted the phrase "Allow Natural Death" to be added to the MOLST form. Paul Ballard said that MIEMSS (Maryland Institute for Emergency Medical Services Systems) would have to approve it.