

State Advisory Council on Quality Care at the End of Life
Minutes from the June 11, 2020 Meeting

Meeting time and place: June 11, 2020, 10:00 a.m., via video conference call.

Council members present: Alan Eason; Paul Ballard (Attorney General's designee); Tiffany Callender; Carol Eckerl; Elena Sallitto; Hank Willner; Geoff Coleman; Marian Grant; Jane Markley; Karen Smith; Yvette Oquendo-Berruz; Stevanne Ellis (Maryland Department of Aging's designee); Steve Glazer; Senator Ben Kramer; Christopher Kearney; Donald D'Aquila; Carol Eckerl.

Others present: Jack Schwartz; Sara Hufstader; Peggy Funk; Phyllis Gray; Niel Rosen; Stacy Howes; Harold Bob; Molly Sheahan; Gail Mansell; Howard Sollins; Ted Meyerson; Dan Morhaim; Elizabeth Clayborne; Jeff Zucker.

Chairman Alan Eason opened the meeting with some brief comments regarding the extraordinary challenges for end of life care posed by the pandemic, noting the shortage of advance directives and the resources needed to provide quality care available in hospitals as well as the severe disparities in health outcomes in minority groups revealed by the pandemic. He invited Council members and guests to introduce themselves, which they did. The Council then approved the minutes for its meeting held on January 24, 2020.

Paul Ballard updated the Council on bills that had been passed by the Maryland General Assembly and enacted into law. He described Senate Bill 576 which authorized nurse practitioners to provide a second certification of incapacity that a patient is unable to make health care decisions and a second certification that a patient is in a terminal condition or has an end-stage condition. He noted that bill also authorized nurse practitioners to provide the second certification of competency in guardian of the person proceedings. He then discussed Senate Bill 402 which authorized health care providers to establish a practitioner-patient relationship through providing telehealth services and that the normal standards of practice apply to such telehealth services. He also stated that the General Assembly required the Council and the Attorney General's Office to prepare a report on how often electronic advance directives are being used and what recommendations could be made to increase their use. Dan Morhaim, Tiffany Callender, Phyllis Gray, Peggy Funk, Niel Rosen, and Jeff Zucker volunteered to join Paul Ballard on the Council's committee that will work on the report. Alan Eason thanked them for volunteering.

Dan Morhaim and Jane Markley discussed National Healthcare Decisions Day. Because of the pandemic, Jane Markley informed the Council that the activities surrounding this annual outreach effort have been rescheduled to July 16, 2020, the day after the new federal tax return filing deadline. Dan Morhaim expressed his hope that the Council could ramp up its activities in promotion of National Healthcare Decisions Day for both 2020 and 2021.

Jane Markley gave an update regarding the progress of the Chesapeake Regional Information System for Our Patients (CRISP) in integrating advance directives from electronic systems into CRISP. She spoke with Nikki Majewski at the Maryland Health Care Commission

and Brandon Neiswender of CRISP. Jane Markley said that MyDirectives.com is the vendor now approved by the Maryland Health Care Commission to integrate electronic advance directives with CRISP. She said there appear to be 2 problems in getting other vendors to be approved for participation. First, most other vendors are not compliant with National Institute of Standards and Technology (NIST) standards because they don't work with consumers and it is financially burdensome for them to become NIST compliant. Second, she said that the Maryland Health Care Commission has no funding to do the integration work needed to add vendors that could potentially be approved for participation in CRISP. Thus, for the time being CRISP is limited to integrating advance directives from MyDirectives.com, potentially limiting the pool of advance directives linked to CRISP. Nikki Majewski told Jane that CRISP is now trying to alert health care providers who participate in CRISP when they need to see a patient's advance directive rather than just simply waiting for the health care provider to look for the advance directive in CRISP.

Phyllis Gray said that MedStar has developed a program called Advance Care Planning identifying patients who need an advance care plan and that they have been conducting tele-visits with these patients. She said they have also created through their Electronic Medical Record (EMR) platform an electronic MOLST form that creates a MOLST form pdf that will also go into CRISP. She said advance planning is extremely important during the coronavirus pandemic and thus Medstar is doing what it can to work with AdVault to integrate MOLST forms across its EMR system. Jane Markley said that Nikki Majewski at MHCC told her that MHCC has no funding to create a MOLST registry on CRISP and no one is pushing for the funding to make this happen.

Jane Markley also reported that CRISP had 2,344 advance directives linked to MyDirectives.com, including electronic advance directive prepared on MyDirectives.com and paper advance directives that were uploaded to MyDirectives.com and linked to CRISP. She said that there is an initiative called Voice Your Choice (www.voiceyourchoice.org) which is managed by Sara Hufstader to increase the number of advance directives in Montgomery County and Prince George's County by getting them completed and uploaded to MyDirectives.com.

Marian Grant said that a large portion of the COVID-19 patients are in nursing homes or are among minority communities. She said that hospitals were able to provide all the care that was needed for COVID-19. The quality of care may not have been terrific because care, including palliative care, was given by a limited staff because patients were segregated in biocontainment units. Hospitals closed visitation to the public. Some were allowing visits at the end of life but patients often died without family members being present. Hospital patients on a ventilator were highly sedated so they were "comfortable." But if these patients were in a nursing home or if they were at home, it is not certain how comfortable they were. Hospices had difficulties seeing people in their homes and family members were unable to visit their loved ones because of protective personal protective equipment (PPE) shortages. Patients who died in Maryland over the prior 3 months did not have what is referred to as a good death in the hospice world.

Marian Grant said the Council could gather information and draft some recommendations for the Governor and the legislature moving forward. She said that hospitals got priority for PPE

but that nonhospital settings did not get priority. She noted that in Connecticut the disabilities community has sued the State to allow caregivers of disabled and dementia patients to be able to accompany them. She said it is going to continue to be an issue that family members cannot visit their loved ones at the time of death, with its resulting detrimental impact on the bereavement process. She wondered what the Council should do in response to these issues going forward.

Elena Sallitto said that she and other attorneys in private practice are trying to get more home-based services financed by the government rather than relying so much on nursing home services. She said from a humanitarian standpoint it is a problem that patients can't see their family members. She said that while it is normally preferable for people to receive care in their home rather than in a nursing home, she doesn't want patients to be sent home from a nursing home if there is a problem getting hospice care in the patient's home because of the issues surrounding the pandemic.

Howard Sollins said there is a lot of concern that visitors were a source of transmission as asymptomatic carriers. He said it is counterintuitive to impose visitation requirements or to lift visitation restrictions without first making sure there is sufficient PPE, the lack of which could create problems for facilities that are already under-resourced. He said that home-based care is an important choice but that often nobody will be home to be there with the patient to deal with wound care or take them to the hospital when they fall. He also expressed his concern that family members may be ill equipped to provide adequate care for a severely immunocompromised COVID-19 positive patient. Elena Sallitto responded that this concern is why funding for home-based care needs to be increased so that people don't end up in that awful situation.

Phyllis Gray said that at MedStar they did have a strict visitor policy but that they did allow up to 2 family members to visit a patient at the end of life unless they were COVID-19 positive, in which case they could come into the hospital but not into the patient's room, and they could communicate through video devices such as computer tablets. They do make exceptions for patients with disabilities that require a family member or for parents of a minor patient. Once they are in the hospital room, they stay there and do not come in and out. She didn't think the visitor policy would change for a very long time until there is an effective vaccine for COVID-19. She said that Medstar's goal was to make sure that every patient's hand was held at the end of life. This was facilitated by the fact that many COVID-19 patients died after terminal extubation from the ventilator. She said the emotional distress for the staff has been very severe because they have never seen such a high rate of death before. Chris Kearney agreed that it has been a difficult time and there has been a lot of grief for family members because they have not been able to talk with their loved one at the end of life.

Howard Sollins said there is some confusion and varying definitions of what it means to be actively dying. He wondered whether there is an assessment tool that could be used to determine that a patient is actively dying and that the patient should qualify for a compassionate visitation.

Peggy Funk said that hospice care programs have had a lack of access to nursing homes and assisted living programs. She said hospice is a Medicare benefit that people are entitled to receive under federal law. But she understood why access is an issue because of COVID-19 and

anticipated that grief will be a big issue as a result of loved ones' lack of access to hospice care patients at the end of life.

Harold Bob said he appreciated that Maryland had been helpful to nursing homes to be more transparent, rather than being punitive. He said nursing homes need 15-minute tests for visitors and a lot of PPE. The CDC is underfunded. He said asymptomatic people are carriers of the coronavirus. He said they have had a lot of problems with County health officers' lack of understanding of COVID-19. He said that we need to stop talking about vaccines because it is unrealistic because there has not been a successful RNA vaccine. He noted that there is still not an HIV vaccine. Instead, this is a long-term problem.

Elena Sallitto asked Harold Bob how staffing level in nursing homes have been affected by the coronavirus. Harold Bob responded that staffing was decimated in all the nursing homes in Maryland. He said nursing homes ended up testing on their own because the County health offices could not provide the testing and the nursing homes also ended up buying PPE on their own. When they started doing testing there were a lot of sick employees. And a lot of employees who were identified as carriers. He said nasal swabs stay positive for 2 to 3 months after the patient is asymptomatic. So, small destroyed viral fragments continue to be positive. He said they still have County health officers asking for 2 negative tests, which just doesn't fit the science. He said that the nasal swab test doesn't turn positive for 4 or 5 days after someone is contagious and the test continues to test positive when people are no longer contagious. He wants to follow the CDC guidelines of 14 days from the onset of symptoms and 3 days without symptoms because the data in multiple sites shows that when someone is post symptomatic 14 days after onset that they continue to have virus fragments but they are not contagious. Chris Kearney reported they are seeing a lot of continued positives for weeks and weeks and they wonder if they'll ever turn negative.

Harold Bob said they are trying to bring staff back wearing PPE but the County health officers are saying the staff can't come back until they have 2 negative tests. He said that there was no way for the nursing homes to prevent these outbreaks. He said that perhaps Maryland could fund PPE and 15-minute testing in nursing homes for family members who want to visit their loved ones. He said Maryland should encourage nursing homes to get hospice and palliative care consults because skilled hospice and palliative care physicians can distinguish between a plateau and real end of life.

Marian Grant asked how the Council felt about making recommendations regarding how to improve care at the end of life during the pandemic. Alan Eason said the Council could distill the issue and he asked Paul Ballard to send an email about what the Council could do. Marian Grant suggested that Paul Ballard could email the Council members to weigh in on their own professional experiences that could form the basis for the Council's recommendations. She discussed an article in the Baltimore Sun that said death rates may not be accurately reported. The Council needs accurate data on who is affected by COVID-19, who is dying, where are they, and what the best kind of care for these patients is regardless of the setting they are in.

Jeff Zucker of MyDirectives.com volunteered to help to research what best practices are used in other states. He said the rest of the world is dealing with this too. He applauded what the

Council and others have done to encourage advance care planning in Maryland. He said if it was easy to solve this problem of increasing advance care planning to get people's voices heard, then the Council wouldn't need to be meeting about this issue. He said he and his company are committed to helping the State of Maryland with this issue, which commitment he felt personally even though he lives in Texas because he had family members who died in Maryland. He said the Council should ask the Maryland Insurance Commissioner to ask CareFirst and other payors to provide insurance coverage to normalize advance care planning. He said that payors in Maryland are behind payors elsewhere in the country on this issue. He said that during enrollment and reenrollment, United, Humana, and other payors outside the United States ask the following questions: "Who speaks for you if you can't speak? How do we reach them? Where is your advance care plan and what are your goals of care?" He said that the payor never needs to know the answers to those questions and just needs to know that those answers exist, that is, that there is an advance care plan. That way the payor could notify the health care provider that the patient has an advance care plan which could be at MyDirectives.com or at any other registry. Physicians need to change their workflow to click the link to MyDirectives.com that is in context on CRISP. Yvette Oquendo-Berruz said that CareFirst would support payors' involvement in advance care planning but they and other payors want to avoid the appearance that they are withholding care from people when that would not be their intent by supporting advance care planning. She said that while she could not speak on behalf of CareFirst, she will see if they might want to take on a greater role in promoting advance care planning.

Elizabeth Clayborne said that quality of care and the advance care plan are linked. She said that the lack of advance care planning creates a barrier to providing quality care. She said that her hospital had a policy that up to 3 family members could physically visit in PPE an actively dying patient in the ER or ICUS at the time of death, specifically for patients who had compassionate extubations. She said that advance care planning allows patients to have good deaths. The main issues she saw with people dying of COVID-19 was that they didn't know who to contact and what the patient's goals of care were, and that this lack of vital information prevents the patients from having a good death. It is vital that nursing homes make sure this information is up to date and made available to the hospital. Because in the absence of this information, health care providers will perform a lot of aggressively painful and unnecessary procedures. She said advance care planning should be accessible at the point of entry into the hospital.

Alan Eason said that the focus should be on insurers. He said that some of what is involved in increasing advance care planning is marketing and finding these entities that people will listen to.

Dan Morhaim said payors have been reluctant to get involved in legislation promoting advance care planning. CareFirst funded research in 2008 about advance directives but got skittish about funding advance care planning. He said that Medicaid participants should also be included. He said that payors have a role that could be beneficial in promoting advance care planning.

Jeff Zucker said that Alan Eason's point about payors and marketing is important. He noted that "death insurance" was not bought by many people until it was renamed as "life

insurance.” He used this as example to show that word choice matters. He said that what works is to include all stakeholders. He said that payors know advance care planning saves money but they want a law to make them do it. That way it does not appear to the public that they want the advance care planning done to make money. He said that the Council should ask the Governor to request that the new Maryland Insurance Commissioner require payors to normalize advance care planning when people enroll and reenroll. It doesn’t mean that enrollees have to consent to advance care planning. Rather, it just means the payor should be required to ask enrollees about whether they have engaged in advance care planning. That way, the payor can say that they are required by law to ask people questions about their advance care planning. This way, payors become part of the solution.

Sara Hufstader said that advance care planning improves the quality of care and patient satisfaction and decreases complaints against health care providers. Alan Eason said that advance care planning also helps families of the patient to better cope with the dying process and makes this experience less bad for the families.

Dan Morhaim pointed to the experience of LaCrosse, Wisconsin, and said the goal in Maryland should be to duplicate their rate of 98% completion, which he noted was greatly facilitated by Gunderson health care being one of their larger payors. Marian Grant said the key to increase participation is to make advance care planning systemic. She is encouraged by what Phyllis Gray and Chris Kearney said about MedStar’s advance care planning efforts because in LaCrosse, advance care planning was started when Gunderson added advance directives to their discharge summary. This put advance care planning into their clinical workflow and prompted staff members to think “I should do advance care planning before I send people out to the hospital”. She said you have to build advance care planning into the clinical workflow and into the EHR, you have to reimburse people, and you have to have time for advance care planning discussions. One of the good results of the pandemic is that the Government authorized people to do advance care planning over the phone and that telehealth may stay permanently after the pandemic is over. She said that she looks for advance directives in CRISP but that it is not useful because the advance directives are not easily accessible and because so few documents are there. She said that in her discussions with the Conversation Project and Respecting Choices that they are overwhelmed by public interest in this topic. She said there has been huge media coverage of advance care planning. She said a lot of people are looking for online solutions because of the difficulties in getting witnesses and documents notarized during the pandemic. She said that system-wide changes to advance care planning are hard to do without a disruption like COVID-19 that may force such changes.

Niel Rosen said that the Respecting Choices program grew out of people’s experiences with dialysis because even though it was predictable that the patient would die and that they would lose capacity, family members still didn’t know what the patient would want. So, Respecting Choices was started to find out what the patient wanted before these predictable outcomes would result. He said that advance care planning should be done within a short period of time after the diagnosis. He said that patients should be educated what the trajectory of their illness is and then their wishes should be ascertained regarding what quality of life is important to them. Clinicians have a clear idea of the trajectory of a chronic illness even though patients often do not. He said that payors could be included when there is a new diagnosis.

Jack Schwartz said in pre-pandemic times that family members could see the care being given to their loved ones in the ICU and develop a sense of what the patient's trajectory looked like. He said that families would then more readily see the need for comfort care if the clinical team came to that conclusion. And now because the family can't see the care being received by the patient, there may be more conflict between surrogate decision makers and clinician's views of the need for comfort care because the surrogate decision maker is not as able to see the likely trajectory of the patient's illness. To address this issue, he asked whether families should be invited to visit and routinely participate in rounds ahead of the point when the patient is actively dying. Alternatively, he asked whether there are best practices in the use of video devices to connect families to what is going on with the patient.

Marian Grant responded that her palliative care team got deployed in April 2020 to be involved in the care of all the COVID-19 positive patients in the ICU and they started making regular phone calls to families. She said that in her 15 years of experience working in palliative care that she had never seen family members that were so prepared for bad news as were those family members she had called over those previous couple of months. Family members are listening to the news, they don't know exactly what is going on with their loved ones, but they are primed for things to not end well. She said they are using computer tablets, calls from chaplains, calls from social workers, and using interpreters when they are needed. She agrees it is not the same as family members being in the hospital in person, but she said that many family members are frightened and don't want to go into the hospital. So, she thought this was probably the best they could do under these circumstances beyond everyone's control.

Elena Sallitto asked Marian Grant if she has gotten pushback from family members regarding proposals to transition the patient to comfort care. Marian Grant responded that she is calling the family members to tell them how their loved one is doing and that the family members are prepared for bad news, and that it doesn't take as long sometimes for them to accept that their loved one who is say, 85 years old with multiple chronic illnesses, is not going to get better from COVID-19. Indeed, family members have sometimes been the ones to initiate the change to comfort care based on what they think their loved one's wishes would be. She said that she had never had so many family members do that before. Phyllis Gray said that had been her experience with families as well.

Chris Kearney said that it may seem to be counterintuitive but having spent a lot of time in the ICU, he has seen the medical teams communicating much better with families and being more proactive in initiating palliative care discussions with families because they have to be proactive during the pandemic. He agreed with Marian that it is surprising how well-informed families have been. He thought that families joining rounds is not perfect. He said that things are not as bleak as you might think. He said that the resident, interns, and hospitalists are engaging in more palliative care discussions now and that this is a bright spot during the pandemic. He thought the Council should recommend that greater community-based palliative care is needed in addition to what is being provided at hospitals. Alan Eason agreed and said it was very interesting to learn from Marian Grant that families were more prepared to see the need for palliative care. He said that palliative care could be incorporated into the Council's outreach efforts.

Phyllis Gray said that MedStar is preparing for how to provide palliative care if there is another surge of COVID-19 in the fall as is expected. Part of this is putting new residents more fully into the palliative care team much earlier in their residency and embedding the palliative care team into the ICU. One advantage of using video devices for the family meetings was that they were able to bring in family members from all over the country into the discussions. She said it was very helpful to have the easy on-demand access to translators that was provided over video devices.

Elizabeth Clayborne said that as an ER physician she has been working on developing a curriculum for providers in how to have advance care planning discussion with families. She said you create a lot of problems if you get off on the wrong foot with a family. She said that semantics, the words you use, and cultural sensitivities are all important. She said that being an African American provider really helps her to connect with families that may not be as trusting of the health care system when talking about sensitive issues. She recommended that the Council talk about how education should be rolled out at different facilities, who should be educated, and how often. She said the Council could recommend a uniform curriculum. She said that families get confused when different providers are saying different things. A uniform understanding by clinicians of how to convey important concepts to families such as what palliative care is, what the goals of care are, and what it means to be a surrogate decision maker making decisions for someone else and not themselves, would all be extremely important to avoid getting off on the wrong foot with families when having these discussions. She said that once that happens it is then very hard to get them to cooperate with the clinical team when they recommend decisions contrary to those the families want to make. Alan Eason agreed with her points and their importance.

Phyllis Gray said that although many COVID-19 patients seen in the hospital did not survive to make it into hospice care, MedStar has been referring survivors to hospice care programs for bereavement support. Hospices are taking care of the families of COVID-19 patients who died in the hospital as if the patient had been in the hospice care program. Geoff Coleman said their hospice program's bereavement team is overloaded and that they are also going to have to treat staff for the mental health issues that has arisen from this very stressful experience of deaths from COVID-19. He appreciated what Elizabeth Clayborne said about the need for more African American physicians in Prince George's County. He said his heart breaks that the family is not allowed to be there with the patient and that typically that an African American family unit is very close. He said that more PPE would go a long way to help solve this problem.

Paul Ballard brought up the issue of pain control that the Council has been reviewing regarding the seeming reluctance of prescribers to prescribe opioids to adequately manage their patients' pain because of fears of criminal prosecution, liability, or discipline from health occupation licensing boards. He said that the Council has floated the possibility of contacting the Physicians Board, the Pharmacy Board, and the Nursing Board about ways to send a more positive message because the feeling is that a lot of people are not prescribing pain medication because of these fears. He said these fears exist despite the existence of legal protections for pain medication prescribed at the end of life, and prescribers do not seem to be well aware of those

protections. He asked whether the Council wanted him to reach out to these other boards. Marian Grant responded that if the issue is not related to COVID-19, people may not be able to review this issue at this time. She said that the bigger issue is that they are running out of opioids at hospitals because of the surge in patients due to the pandemic.

Dan Morhaim said that there were bills between 1998 and 2001 that promoted the use of pain medications and those efforts were funded by drug companies. He voted against all those bills because he thought practitioners were handling pain just fine. But these efforts by the drug companies were successful and led to the overprescribing of opioids. The pendulum has swung back in the other direction of too many opioids being prescribed. He said that opioid deaths have gone up 2½ percent. He said that clinicians should be allowed to manage pain because they generally do a good job, don't withhold needed pain medications, and don't require a lot of government interference, especially in the areas of hospice, palliative care, and emergency medicine. He said that medical cannabis is another way to manage pain.

Sara Hufstader said it is important for person's voices to be heard regardless of whether they want more aggressive care or less aggressive care or whether it saves money. Jeff Zucker agreed it is about patients getting their voices heard so that health care providers can do a better job respecting their patients' treatment wishes and getting to a more patient-centered health care experience. Alan Eason said that when he makes presentations to people about the importance of advance directives, he emphasizes that there are no right or wrong choices except for what the person wants and that advance directives empower patients to have their wishes in place even after they lack the capacity to accept or refuse treatment. Jeff Zucker pointed to his MyDirectives wallet card and his insurance card that has his MyDirectives information coded on it that could be scanned, as well as his Texas driver's license that has bar code on the back of it that can be scanned. He said the solutions are there and it is just a matter of implementing them in Maryland so that more people prepare advance directives that can be readily accessed. He believed that step by step Maryland can get to where it needs to be on advance care planning.

Elizabeth Clayborne offered to participate in the Council's activities and contribute her perspectives as an emergency physician who has a background in bioethics. She said she does a lot of work related to end of life care and advance care planning and she has a lot of sensitivity to our minority populations which are currently of supreme importance and to make sure we are culturally aware and sensitive to the uniqueness of the American population when dealing with these issues. Paul Ballard enthusiastically welcomed her participation in the Council's activities.

Jeff Zucker noted the severe mental health crisis that is occurring as a result of the pandemic and that MyDirectives has been getting many more mental health wishes uploaded on videos to its website. He thought it would be beneficial if there was a way to also incorporate those mental health wishes into CRISP. Paul Ballard noted that Maryland law does provide for mental health advance directives and such wishes could also be included in other advance directives (though he acknowledged that perhaps this is not yet included in CRISP).

There being no further business, Alan Eason adjourned the meeting.