

State Advisory Council on Quality Care at the End of Life
Minutes from the September 9, 2020 Meeting

Meeting time and place: September 9, 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; Stevanne Ellis (Maryland Department of Aging's designee); Senator Ben Kramer; Christopher Kearney; Donald D'Aquila; Susan Lyons.

Others present: Jack Schwartz; Sara Hufstader; Peggy Funk; Molly Sheahan; Gail Mansell; Howard Sollins; Ted Meyerson; Dan Morhaim; Elizabeth Clayborne; Jeff Zucker; Carrie Durham; Evan Derenzo; Karren Pope-Onwukwe.

Chairman Alan Eason opened the meeting with some brief comments regarding the prior Council meeting, praising the quality of the discussion. He introduced Susan Lyons, a new Council member, who is a nurse practitioner. She said she has worked in a hospital in Hagerstown for over 30 years. Her experiences as a critical care nurse with many unsuccessful resuscitations in the 1990s (when there were not many DNR orders in existence) prompted her to get involved in the field of palliative care. She became a nurse practitioner who coordinates inpatient palliative care services at the hospital. She was also selected to be a Maryland MOLST trainer in 2013 to help train as many people as possible in the State of Maryland in advance care planning and the MOLST form. Although she works on the inpatient side and serves on the hospital's ethics committee, she is also now working more on advance care planning initiatives in the community. Her goal is to normalize advance care planning conversations in the community. She said that most people are happy to have these conversations, especially elderly patients who are relieved that someone is asking them. She is happy to join the Council.

Jack Schwartz spoke about the allocation of scarce resources in hospitals during the pandemic. He said that a second surge of COVID-19 is possible in the Fall or Winter that may be worse than the surge experienced in the Spring of 2020 and it may become necessary to allocate scarce critical care resources such as ventilators or adequately staffed ICU beds, and then determine who will get these resources and how these decisions will be made. He said that after the H1N1 pandemic in 2009, this issue was explored by a number of expert groups across the country, including an effort in Maryland led by researchers at Johns Hopkins. He said that a report had been issued in 2017 regarding how to determine which patients should receive scarce critical care resources like mechanical ventilators. This report also included feedback from focus groups consisting of citizens from across the State of Maryland regarding the ethical issues raised by a situation in which scarce critical care resources may have to be allocated.

From the work done by the Hopkins research group and other similar groups of experts across the country, certain principles have emerged, which consist of three guiding principles: (1) Save as many lives as possible by saving the most savable lives; (2) To the maximum extent possible, use objective clinical criteria to protect against biased decision making, that is, by using

the Sequential Organ Failure Assessment (SOFA) which is the only available clinically objective measure of who is getting better or who is getting worse (which assessment tool is used to produce a SOFA score for each patient regarding who is most likely to benefit from a critical care resource in terms of short-term survival); and (3) Decisions should not be made at the bedside by attending physicians but instead by a triage officer not in a direct clinical relationship with the patient and who has broader knowledge of what's going on in the hospital.

Jack Schwartz said there are many challenging ethical issues arising from the potential situation of scarce critical care resources. He said it is foreseeable that when you use an objective scoring measure like SOFA that you are going to wind up with ties between patients with the same scores, and then what do you do to decide who gets the resource? What are the tiebreakers? One intuitive tiebreaker is longer-term survival but using too long a time horizon would unfairly penalize people with chronic comorbidities. Focus groups favored younger patients over older patients as a tiebreaker but such reliance on age would raise both ethical and legal concerns.

Jack Schwartz said that during the Spring surge of the pandemic, physicians from 5 health care systems, including the 3 largest, have collaborated to develop operational guidelines for allocating scarce resources. They began with a focus on ventilators, which during the early stages of the pandemic were considered to be the most critical resource. But especially as physicians learned how to better care for COVID patients, the issue of ventilators somewhat receded and now the issue is more about having adequately staffed ICU beds, hospital beds generally, and modalities such as dialysis or convalescent plasma. They collaborated to pool their expertise with the goal of having as much uniformity across these hospital systems as possible in the event that such a shortage of critical care resources were to occur. This is an ongoing process and they see this as a quality improvement initiative for an event that they hope never happens but want to anticipate as best they can and plan for it. So, the draft guidelines contain answers to the questions "What are the objective criteria we apply?" and "How does the triage process work?" The guidelines also provide scripts for communicating to patients or families in these circumstances. So, it is an important document and one that is ongoing in its development. And he wanted to inform the Council of the development of these guidelines because of their importance and to bring to the Council's attention some of the issues raised by their development.

The first issue is transparency. The development of guidelines within these 5 hospital systems was seen as an internal process driven by clinicians looking ahead to a dire clinical situation. They did not see this as a public process but have shared their draft guidelines with the Governor's office because in the end if the use of these guidelines become necessary, it is the Governor who is the ultimate decision maker. He said that he and many others believe that interested persons such as Council members, hospitals that are not part of the workgroup, and members of the public should also be allowed to look at these draft guidelines and offer their thoughts. The Maryland Health Ethics Committee Network, which is a membership organization of member facilities' ethics committees, believes that the draft guidelines should be posted on a website so that people can look at it (without the State necessarily adopting it).

The second issue concerns triage. The Maryland Health Ethics Committee Network also asked the Governor to appoint a broadly representative statewide triage committee. Thus, in the event of rationing there would be someone outside of any given hospital or hospital system that had an overview of what was going on, could collect data, and monitor how the guidelines were being applied.

The third issue of particular pertinence to the Council is that if this were to happen there needs to be a surge capacity for palliative care, for hospice services, and for spiritual care because patients and families who are seeking the most aggressive care possible would be told they can't have life-sustaining treatments because of the rationing of care.

Howard Sollins asked about the part of the proposal regarding a triage process external to the health care facilities. He noted that historically these issues are handled internally in the facility through its patient care advisory committee. He asked why this would be different in this situation. He also asked whether the thinking in favor of an external triage process is because from a liability protection standpoint, actions taken under these guidelines would qualify as good faith efforts under the existing statute for emergency management protection.

Jack Schwartz said that the draft guidelines that the hospital systems have developed and that the Hopkins researchers developed in their 2017 report both envision that each hospital would have its own triage committee but not an explicit role for the ethics committee, even though typically someone from the ethics committee would be involved. Under the proposed processes, the triage decisions would take place internally at the facilities. If there were a State triage committee, it would have a broad oversight role but no one envisions that the State triage committee would make decisions for particular patients. The facility's triage committee would make their decisions based on objective clinical data. The facility triage officer needs to be a clinician who is able to understand the import of the SOFA scoring for particular patients. Regarding liability, the Governor invoked the Catastrophic Health Emergency Act when he declared the emergency related to COVID-19. That emergency remains in effect and has liability protections derived from it. Whether those liability protections would apply depends on what actions the Governor takes in the face of the need to allocate scarce resources.

Stevanne Ellis asked whether Jack Schwartz could send out the draft guidelines. He said he has seen earlier versions but he saw them under conditions of nondisclosure and thus cannot share them. Jack Schwartz said he would send the letter to Paul Ballard that the Maryland Health Ethics Committee Network sent to the Governor. He also offered to send copies of letters that Disability Rights Maryland and an aging advocacy group sent to the 5 hospital representatives regarding the proposed guidelines. These letters expressed their concerns regarding disabilities rights and aging issues raised by the draft guidelines. She asked if he could send information about SOFA too and he agreed.

Elizabeth Clayborne said that as someone who helped to draft the scarce resource protocol for her hospital, she did take a look at the draft guidelines. She said as a clinician who was a front-line provider when the pandemic started, some of the challenges presented were how these decisions were going to be made in a practical real-world situation. For example, the SOFA

score in the emergency department is not as practical as it might seem because it requires a lot of clinical data and past medical history not available in the emergency room when a patient is in respiratory distress and they have to decide whether to intubate the patient. A clinician is not going to be comfortable making a last-minute decision without enough information. One of the key ways to prevent this problem in a scarce resource situation is having an advance directive to know what the patient would want. If she had access to an advance directive for every nursing home resident that came in, which she does not always have, it would save her a lot of heartache in having to decide whether or not she was going to intubate someone in the five minutes that she has to make that decision when they arrive.

Jack Schwarz agreed that advance care planning ought to be seen as part of surge capacity because eliciting people's treatment preferences prior to the critical care scenario is every bit as important as ventilators and field hospitals. He acknowledged that if information needed for a SOFA score is not available in the emergency department in the same way that it might be available in the ICU, the patient may need to be intubated and the issue of rationing may need to be sorted out afterwards when a quick decision is needed and the patient does not fit into the guideline.

Howard Sollins asked whether there was any thinking that the MOLST form needed to be tweaked or have a special addendum to address short-term intubation as opposed to intubation in the context of long-term life support. Marian Grant said that is a good question but that we would not be able to change the MOLST form in time. She said that minority communities must be included in the discussion of allocating scarce resources, especially because they are being impacted by COVID to a greater extent than other communities. Jack Schwartz said that in the Hopkins project there were a series of focus groups that had geographic, racial, and ethnic diversity. He agreed that the choices being made here are of societal importance and not just for experts. The reason the Maryland Health Ethics Committee Network has urged the Governor to make the draft guidelines public is so representatives of various groups can have a chance to comment on them.

Dan Morhaim said as an emergency room doctor he spends a lot of time scrambling for information even under normal circumstances. He said a patient should put together their own medical "go bag" containing name and contact information, a copy of their recent EKG, a copy of their most recent lab test, a copy of their advance directive, and then hand the "go bag" to the ER doctor. This can save a tremendous amount of time for ER doctors and would be helpful. He said you can't get all the patient's medications on CRISP and this is a way people can plan to provide information to ER doctors whether or not there is a pandemic.

Hank Willner asked if there is an advance directive at MyDirectives.com, is it automatically uploaded to CRISP? Jack Schwartz said advance directives are uploaded to CRISP. He said it only took his primary care provider 2 or 3 clicks to get to his advance directive on CRISP. Jeff Zucker said that MyDirectives is sending everything to CRISP. He said that CRISP is working though some of their own technical challenges to make sure everything that it is getting from MyDirectives, CRISP is then able to deliver to the hospitals. He said that you can upload any advance directive document on to MyDirectives.com, and then MyDirectives gives a

notification to CRISP so that any time there is a patient record accessed in Maryland it is querying that. He said MedStar went live querying for MOLST documents too and those MOLST documents are tagged in the AdVault database so that CRISP can query and pull those documents as well. He hoped that what MedStar has done will be repeated elsewhere in Maryland. He said the ethical challenges are greatly reduced when doctors have real time access to patients' goals for care which speak for them. Anything that helps increase the scope of advance care planning really helps providers solve these difficult ethical scenarios.

Christopher Kearney said MedStar is now creating electronic MOLST forms in the medical record and immediately creates a pdf MOLST form, which has been a good step. He said there was rationing going on in the height of the COVID pandemic in terms of moving patients from various facilities to other facilities far away from their homes. This would result in families not knowing where their loved ones were being treated, for example a family member in D.C. may not have known that the patient was moved to a hospital in Baltimore. Given that things have calmed down for the moment, he asked about the current status of the allocation guidelines. Jack Schwartz said that he offered issues for the Councils' consideration but didn't offer what the Council should do because he wasn't sure what the role of the Council would be. He suggested that perhaps the Council might want to support the Maryland Health Ethics Committee Network's request for transparency. Mainly, he presented the issue to the Council because he thought it was important to brief the Council.

Alan Eason said knowing what an advance directive says may free up scarce resources because some patients may not want certain life-sustaining treatments. Jack Schwartz responded that that would be a desirable effect. He said that the discussion of goals of care is the responsibility of treating physicians and is separate from the question of the allocation of scarce resources. But the focus of the treating clinician should be on eliciting patient's goals of care without thought to the issue of the scarcity of resources. Rather, the scarcity of resources issue should only be for the triage team to consider separate and apart from any discussion of the patient's wishes. Alan Eason acknowledged the importance of keeping those processes distinct and separate but made the point that if advance care planning is done properly, the result might be to also free up scarce resources. Jack Schwartz agreed. Marian Grant said the rate of advance care planning is not going to change substantially by this Fall and that providers have to prepared to deal with that reality.

Sara Hufstader, Lead Project Coordinator, presented to the Council regarding the Voice Your Choice (VYC) program. The program provides information and training to guide the user how to create an online advance care plan or upload an existing advance care plan that will integrate with the Maryland Health Information Exchange, that is, CRISP. The mission of the Voice Your Choice Program is to motivate people to express and document their healthcare wishes when they can't speak for themselves. A major focus is educating individuals on how to choose their health care agent so that the agent is able to advocate for the person and adhere to their wishes. They do a lot of community outreach, including through webinars. They also educate health care providers regarding advance care planning and to let them know that the program is working with the community to create these online advance care plans on a platform

that is integrated with CRISP, and to let them know they can start looking for these advance care plans in CRISP.

Sara Hufstader said that although the Voice Your Choice Program had been doing a lot of training in person prior to the pandemic, they now offer four different webinars, three for the community and one for providers. They also do a lot of public education and promote awareness through educational opportunities that arise as well as in marketing the VYC program. Their target population in Montgomery and Prince George's County are all adults 18 years and older, not just older adults, who they encourage to think about appointing a health care agent and documenting their health care wishes. They provide access to a free online planning tool through a contract with MyDirectives.com and they have personalized that tool to call it the Voice Your Choice online platform. These advance care plans are then integrated into CRISP, which makes these plans more accessible for health care providers and hospitals and that gets around the interoperability issue and is thus portable across care sites.

She said the program is funded by Nexus Montgomery and is led by the Jewish Social Services Agency (JSSA). The Voice Your Choice Program integrated all the recommended best practices for advance care planning, including interactive sessions with a knowledgeable presenter, Internet and repeated interactions, use of technology and engagement of both the community and providers, and expanding advance care planning from medical institutions into the community. Voice Your Choice has a website www.voiceyourchoice.org that has the online platform that is integrated with CRISP, resource sheets, including advance care planning and COVID-19 resources, as well as a sheet that talks about an advance plan versus the MOLST form. She said that members of the community and some providers are confused about the differences between advance care planning and MOLST forms and so their presentations discuss the differences between the two.

Registration for the community and health care providers can be found on their website. They are developing a "how-to" guide to help people create an online advance care plan. VYC is also working on translating their materials into many other languages, including Spanish, French, Chinese, Russian, Korean, and Vietnamese. Their website is directed at 3 main audiences: the community, providers, and community partners. All their resources are provided for free and can be shared. Sara asked that if they are shared, to let them know where so that they can let their grant funder know where the resources are being used. People can upload their advance care plans onto the website's advance care plan platform that is linked to CRISP. Their live webinars are recorded and are available on their website.

Alan Eason introduced the topic of the General Assembly's directive to the Council and the Attorney General's Office to prepare a joint report regarding how electronic advance directives are being used and what recommendations can be made to increase their use. The Council formed a workgroup to develop the report. Tiffany Callender updated the Council about the electronic workgroup's progress. She said the workgroup's focus was on uploading electronic advance directives. She said an attorney from MedChi is doing background work to look at what has been done in other states. To look at what legislation has already been proposed

here in Maryland, and to look at whether other states have successfully required notations of advance directives on drivers' license.

Tiffany Callender said the workgroup is looking at ways to embed, standardize, operationalize, and normalize advance care planning. They are looking at ways to upload the existing one million advance directives in Maryland onto electronic platforms, at ways to embed this process in partnership with payors, and at the possibility of advance care planning being added to payors' individual incentive programs. Also, they are looking at whether advance care planning can be embedded into processes where individuals interact with State agencies, for example, when a person applies for State benefits they could be presented with an opportunity to complete an advance care plan.

She said the workgroup is revisiting the possibility of including driver's advance directive information when they renew a driver's license or when they sign up to be an organ donor. So, the workgroup is exploring opportunities for making advance care planning a standard process, which opportunities could be reported to the legislature. The workgroup has also considered how National Health Care Decisions Day could be used to help promote awareness among Maryland residents of the importance of advance care planning. Also, it may be helpful to approach large organizations, employers, and health care systems about whether they have their own HR internal practices to promote advance care planning. The workgroup will begin the report based on the foundation of the background research conducted by MedChi's attorney.

Dan Morhaim said he checked with his connections at Kaiser Permanente to see how they are approaching the issue. He said they have a closed system. There is a pediatric ophthalmologist with Kaiser, Dr. Joseph Territo, who leads their efforts on this issue. Kaiser is pushing their providers to engage in advance care planning and is setting up an internal electronic advance directives system. To date they only have 5% of their patients with advance directives that are in the electronic medical records system. Because it is a closed system, Kaiser has an opportunity with every interaction with patients to include the topic of advance care planning. Dr. Territo has agreed to be part of the workgroup. The workgroup may be able to learn some lessons from what Kaiser is doing. One of the challenges that Kaiser faces is that it does not operate hospitals in Maryland like it does in California, so their medical records are not always at the hospitals used by their patients. Thus, they also have to figure out how to communicate with those hospitals. Dan Morhaim has also been in touch with DaVita, the largest dialysis entity in the U.S. He said DaVita is beginning to figure out how to promote advance directives and MOLST forms. He also responded to Marian Grant's comment earlier in the meeting about the difficulty of changing the MOLST form during the pandemic. He said that the Council might also want to take a look at the MOLST form to see if there might be changes that could be made to the form to accommodate what has been learned during the pandemic.

Tiffany Callender updated the Council on the work of Speak(easy) Howard. She said they have almost 30 grantees that they work with now. Speak(easy) helped Howard County General Hospital change their internal practices regarding advance care planning. She said that Speak(easy) funded MedChi to get legal help so that the Council could get the work on the report

to the General Assembly started and so that the Council could make recommendations regarding how we can standardize electronic advance care planning for the State.

Tiffany Callender said Speak(easy) still highlights the importance of naming a health care agent as a top priority. But they changed their website to highlight “caregivers” and “estate and will planning” because they saw that people in Howard County were not doing Internet searches about advance care planning but were instead doing searches about caring, caregiving, and estate planning for how to prepare a will. So, Speak (easy) changed the website to meet people where they are regarding what information they are seeking online. For example, when someone wants information about how to help their parent, they want to be able to answer that request. So, the website is now designed to be more comprehensive to include caregiving and other issues of concern to the user.

The first thing that the Speak(easy) website tells people to do is to name their health care agent. So, they are still providing the message regarding the importance of advance care planning but are putting it in the context of what people are organically looking for. They also talk about completing a living will and getting clarity on what your loved one wants. They provide information on local support groups. If a person wants to do estate planning, that person is going to get 5 tips on estate planning, the first tip being to name their health care agent. Speak(easy) has also created a series of videos on the website that are unique to the pandemic and that highlight the importance of different things you should do during this time. They did this by asking people in their grantee groups to record these videos in their homes regarding why advance care planning was important now and in the future. They also made other relevant videos such as visitation rules during the pandemic. Their statistics show that people are watching all of these videos which are extraordinarily useful during the pandemic.

She said that Speak(easy) also provided a grant that helped 3 major medical practices in the County to embed advance care planning in their processes. Thus, even more providers have operationalized advance care planning within their organizations. Howard County government has agreed to include Speak(easy) within their open enrollment in 2020. They also gave a grant to MedChi to develop a standardized advance care planning process statewide. They also planned an event on September 30, 2020, called “Speaking Easy Over Dinner” to create a time to have a meal with family members to have the advance care planning conversation with them. They deliver a meal to the person who can have that conversation with their loved one remotely while having that meal. As of the time of the Council meeting they already had 60 people registered for dinner kits to be delivered throughout Howard County. On that date, a website will open up a “menu” that creates questions to facilitate discussion of the advance care plan during the “appetizers” (for example, say “when have they been most comfortable in their own skin”, “what gives them peace?” “what matters to them?”), the “entrée” (talking about their values and what they want people to decide for them regarding medical decisions if they could not make these decisions themselves), and “dessert” (naming your health care agent). Then they are pointed to the MyDirectives website so that they can electronically name their health care agent.

Dan Morhaim asked whether Speak(easy) has tracked how many people in Howard County have gone on to MyDirectives. Tiffany Callender said MyDirectives.com can track

whether the advance directive came from the Speak(easy) website. She said Speak(easy) is focusing on making institutional changes to operationalize advance care planning in addition to raising awareness of advance care planning through the community. Dan Morhaim said everyone has tried various methods to increase advance care planning participation, so it is important to have measurements of what has been effective across diverse communities. Thus, he said that the measurements that Speak(easy) generates will be helpful. Alan Eason praised Speak(easy) for paying attention to feedback they receive from the community and taking actions accordingly to better focus their efforts on encouraging people to engage in advance care planning.

Alan Eason raised the topic of a recent AARP video presentation on advance care planning in which he, Jane Markley, and Paul Ballard participated as presenters. Ted Meyerson said this presentation was part of a series of video presentations produced by AARP as part of its National Health Care Decisions Day educational efforts. He said Dan Morhaim and others have participated in additional presentations. Ted Meyerson praised all the panel participants and said that the video presentations can be found on the AARP Facebook page, or they can be accessed at AARP on Outlook online. He said they will be recording more video presentations, including on hospice care.

Alan Eason invited people to suggest agenda items for future Council meetings. He also thanked Marian Grant for her contributions to the Council over the years. Alan Eason then adjourned the meeting.