

## State Advisory Council on Quality Care at the End of Life

### Minutes from the April 20, 2023 Meeting

Meeting time and place: April 20, 2023, 10:00 a.m., the Office of Health Care Quality, 7120 Samuel Morse Drive, Second Floor, Columbia, Maryland, and via video conference call.

Council members present: Christopher Kearney; Paul Ballard (Attorney General's designee); Jane Markley; Peggy Funk; Gail Mansell; Tiffany Callender Erbeling; Nicole Lopez de Victoria; Susan Lyons; Tricia Nay (Maryland Department of Health's designee); Sara Hufstader; Donald D'Aquila.

Others present: Steve Levenson; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Alexandra Baldi; Steve Levenson; Kathy Ware; Stacy Howes; Remo Rios; Jenny Kraska; Tashi Taliaferro.

Chairman Christopher Kearney opened the meeting. The March 2, 2023 minutes were approved.

Dr. Steve Levenson presented to the Council regarding health care decision-making capacity. He said he had been involved in various aspects of end-of-life decision-making in Maryland since the late 1970s. Most of his career was spent as a long-term care and post-acute care medical director. In that capacity he has interacted with and had patients from almost every hospital in Maryland and from many other health care settings in Maryland. One of the things that has been of interest to him since the 1970s is the ethics of decision-making. He has learned that there are certain universal and enduring processes involved in healthcare decision-making that apply everywhere and don't really change much with time. He thinks these universal principles that form the foundation for the Health Care Decisions Act, MOLST, the patient advisory care committee laws, and a number of regulations regarding health care decision-making have stood the test of time pretty well.

He has attended the Council meetings lately and one of the issues that keeps coming up is who can certify decision-making capacity. It occurred to him that there is a lot more to this than meets the eye and this question of who can certify decision-making capacity is just the tip of the iceberg. The universal steps in the health care decision-making process include defining decision-making capacity and its many implications. The first step is to identify people's wishes regarding life-sustaining treatments and situations where the discussion of life-sustaining treatments ought to be discussed even if people don't know that they should do it. The second step is to obtain existing care instructions such as advance directives and to a certain extent the MOLST form, although the MOLST form is really more about implementing the care decisions than it is about obtaining them, although it is based on obtaining them. The third step is to clarify the relevant medical issues, including physical condition, prognosis, and decision-making capacity. The fourth step, to define decision-making, is not purely a medical issue, although it is highly dependent on the brain, the rest of the body, such as the endocrine system, the renal system, and everything else. So, health care decision making capacity has major physical and medical underpinnings even though truthfully you don't need to be a clinician to determine decision-making capacity. Once decision-making capacity is defined, the important part is to try

to optimize it. And then the next steps are to identify the primary decision maker and certify qualifying conditions, and to discuss and define the issues and laying them out in detail with the patient or the primary decision maker, matching medical findings with the individual's values, goals, and wishes, and then implementing treatment options. So, actually, as a major participant in the development of MOLST in Maryland, he said that the MOLST form is the implementation of the healthcare decision process. Then, finally the situation is reviewed periodically, and the approaches used are continued or modified as appropriate. Decision-making capacity can be done by non-medical practitioners, and he has seen it done very well by social workers, for example. It is essential to optimize patient participation in healthcare decisions. Decision-making capacity is not the same as legal competence or mental status. The adjudication of incompetence is not routinely necessary and is harder to reverse if the patient's condition changes. Decision-making capacity is not a medical decision but has inescapable medical influences.

The healthcare decision making process needs to be done to a certain extent sequentially and that is one of the challenges that practitioners face in all settings, that is, to not skip steps in that process. Decision-making capacity is three dimensional and often usually needs to be evaluated across time, not just at one moment. Unfortunately, a practitioner may see a patient at one point in time for 5 minutes and not get the whole picture. There are a number of factors that can affect decision-making capacity including delirium, recent illness, and medication effects, that need to be taken into account. There is a need to assess or confirm capacity initially (for example, upon admission) and periodically thereafter. Decision-making capacity can fluctuate and change over time. So, an important step is to reconcile diverse opinions. The previous assessment of decision-making capacity may need to be reversed depending on the situation, and he said he had to do that about 10% of the time in his practice over the years when determinations of capacity had been made in a different setting. The patient's condition may have changed since they were in the hospital or elsewhere, or medications may have been added, or there may have been improvements in their medical condition, etc.

The Health Care Decisions Act requires certifications of incapacity, and that Act went into effect in October, 1993. So, this is not a new issue. The information about decision-making capacity will be relevant to many situations, not just end-of-life situations. There needs to be some documentation for conclusions that support those conclusions, which is only done sometimes because it is not really mandated. Sometimes, people just check the box. Then the decision-making capacity needs to be reassessed or confirmed. So, an important part of all this is not just certifying incapacity but looking at the factors that affect decision-making capacity such as underlying causes of lethargy, confusion, delirium, and some of those causes can be readily addressed. Among these causes that can be readily addressed are medications. He has seen a number of patients with hypothyroidism or incompletely treated thyroid disease that was made worse by their acute illness. For example, he had a patient once in her early 60s that was pretty psychotic and everyone said she had dementia and she lacked capacity, etc. but she actually had hypothyroidism and was on the medication Synthroid and Ativan and a whole array of medications that had been prescribed for her at the hospital that she came from. It turned out she wasn't getting enough of this medication to treat her hypothyroidism and as a consequence she was psychotic. Thus, this was a medical problem that was causing functional and psychological impairment. Once he put her on a proper dose of Synthroid after having had to put her on an

antipsychotic for a month, her decision-making capacity was improved through proper treatment of the underlying physical foundation. We want to maximize the patient's role in decision making, and the patient will play a more or less substantial role in their decision-making, even when someone else becomes their decision maker.

Back in 1988, there was a fundamental article published in the New England Journal of Medicine that gave the four determinants of decision-making capacity: (1) evidencing a choice, that is, actually making one, (2) factual awareness of issues, (3) rational manipulation of information, and (4) appreciation of the nature of the situation. So, it isn't just a mental status exam, and it isn't just a medical exam. The use of this criteria has stood the test of time. In 2011, the Journal of the American Medical Association published an article titled "Does This Patient Have Medical Decision-Making Capacity?" He said it is a great article because it talks about the whole issue. One of the things it says is that clinicians recognize the lack of capacity in only 42% of patients. The authors used the word "clinicians," so it didn't just apply to physicians. What that tells us is this is not a new issue. It has been brought up many times at the legislature and through proposed laws that someone has got to certify that the patient lacks decision-making capacity. The challenge is that as a process it is considerably less than optimal. So, quality assessment of decision-making capacity isn't dependent on the practitioner's degree. Rather, it has to do with following the steps. The article mentioned the Aids to Capacity Evaluation (ACE) which is a published tool that has been around for a while and that has some evidence to support it. And this tool is available free online just by typing in "Aids to Capacity Evaluation tool." It is a useful tool to summarize the various factors and issues in determining decision making capacity.

There are many implications of certifying that someone lacks decision making capacity or certifying that they have capacity, and include making, updating, or revoking an advance directive, appointing a health care agent, making specific treatment decisions, and accepting, refusing, or declining medical treatment, care, or discharge. He said there are many questions related to the Health Care Decisions Act, and MOLST, including who can decide that a patient has lost capacity, what are the requirements regarding written certifications of incapacity, what is required for the declarant to be emotionally and mentally incompetent, and does a certification of incapacity apply when someone is transferred to another setting?

Medications are a very strong factor in affecting a patient's decision-making capacity. He often saved patients from oblivion by addressing the adverse consequences of medications. Substance use issues, sensory limitations, social, psychological, environmental factors, language, culture, etc. are all factors affecting decision making capacity. He cited a 2008 article from The Medical Letter titled "Drugs That May Cause Psychiatric Symptoms" showing that there are many commonly used medications that impact behavior, mood, and cognition.

He said there are nine steps in the health decision making process that are universal and enduring. So, the question always arises as to how we can improve the implementation of people's rights to make decisions and make sure their wishes are turned into action. He believed that adherence to these nine steps gives practitioners the best chance of turning patients' treatment wishes into appropriate matching medical actions and that to fail to perform any of these steps increases the likelihood the medical actions won't match the patients' treatment

wishes. The improvement of practitioners' compliance with all of these steps would greatly improve the chances that treatments match the patients' wishes and he urged the Council to promote the use of these steps in the healthcare decision making process to be done right and better by practitioners all throughout the healthcare system. The matching of patients' wishes to the treatments they actually receive will never get better until the healthcare decision making process is done right and consistently by practitioners.

Christopher Kearney agreed with the complexity of assessing decision-making capacity as described by Steve Levenson and that it is very common for a patient to go back and forth in the hospital between having decision-making capacity and not having capacity. He agreed with Steven Levenson's conclusions that the healthcare decision-making process is an ongoing one with many complexities and that Steve Levenson helped the Council understand just how complex it is.

Paul Ballard gave a legislative update to the Council. He said there wasn't a lot of legislation that passed that was relevant to the Council's work. He said that Senate Bill 154 regarding mental health advance directives had passed. He said the Council had previously discussed a technical issue in the bill that he brought to the legislature's attention, namely that it directed the Behavioral Health Administration to study the feasibility and costs of incorporating mental health advance directives into the State's advance directive registry (which does not exist) rather than through the State's advance directive program coordinated by the Maryland Health Care Commission. The bill was corrected to have the Behavioral Health Administration and the Maryland Health Care Commission jointly study how first responders and behavioral health crisis providers can access the advance directives database developed by the Maryland Health Care Commission in collaboration with the State-designated health information exchange when responding to a behavioral health crisis. He speculated that perhaps passage of this bill may focus more attention on the advance directives database and the importance of having it up and operating in good shape.

Paul Ballard said that the cross-filed House Bill 157 and Senate Bill 98 regarding geriatric and medical parole did not pass. He said that the cross-filed House Bill 722 and Senate Bill 845 that in part would have authorized physician assistants to provide the second certification of incapacity also did not pass. He also reported that the End-of-Life Options Act, cross-filed as House Bill 933 and Senate Bill 845, regarding aid in dying, failed to pass. He understands it will be introduced again. Senate President Bill Ferguson was reported in the Baltimore Sun as saying it would be a major issue in the 2024 session.

Christopher Kearney asked Paul Ballard how the Council should be monitoring the impact of Senate Bill 154 regarding the potential inclusion of mental health advance directives in the advance directive database. Paul Ballard responded it would be part of the Council's general monitoring of the impact of the advance directive database being developed by the Maryland Health Care Commission. Jeff Zucker said the Council should monitor that sufficient safeguards are put in place to ensure that the mental health advance directives and other advance directives placed in the database were up to date and actually completed by the patients, and that patients would have the ability to become aware of, and object to, advance directives they did not actually complete. Christopher Kearney asked if Paul Ballard had any comments about

preserving the integrity of advance directives in the potential database. Paul Ballard said that he did not have any comments about that issue and simply noted that although mental health advance directives are not directly related to the Council's mission to monitor care at the end of life, because they will be part of the advance directives database the Council will need to monitor all the issues surrounding the database, including those concerning mental health advance directives that are put into the database.

Peggy Funk said she understood they were trying to connect the uploaded advance directives to the CRISP system and asked whether that had been done so that you can now see the patient's uploaded advance directive through CRISP if you're an emergency room doctor. Christopher Kearney said that the answer is not always. Peggy Funk was wondering what kind of progress the Maryland Health Care Commission has made with fulfilling that objective. She also wondered what kind of progress has been made in collecting advance directives electronically and she would like to see the baseline number when we started and where we are now in 2023. She was also curious regarding how many updates to those advance directives have been made during that time to see if people are going into the system and updating the advance directives as needed. Also, she wondered if advance directives can be uploaded from various platforms like MyDirectives, Five Wishes, etc. She would be very curious to know exactly where they are coming from. She said it would also be interesting to see uploaded advance directives by income to see who are actually uploading advance directives onto CRISP and what areas of Maryland are underserved. Susan Lyons commented in Chat that "When we started scanning advance directives in EPIC four years ago, we started at 12%. Presently, Meritus Medical Center has 24% advance directives on file for adults over age 18."

Paul Ballard suggested it would be very useful if Peggy Funk and Jane Markley put together a list of specific questions they have for Nikki Majewski at the Maryland Health Care Commission. He said she is very responsive, and she apparently has a lot of data. He suggested they put together one letter for the Council to send to the Commission that is very clear regarding what information the Council would like to obtain from the Commission.

Jeff Zucker responded to Peggy Funk's questions by saying that the last time he saw data from the Commission that the advance directives were only in the single thousands which is not enough given the estimated 4 million people in Maryland over the age of 18. But the technical workflow is there for free for the consumer to use whatever advance directive form they want, Five Wishes, prepared by their lawyer, anything on paper, etc. or they can complete one digitally on MyDirectives.com, store it for free, and then CRISP can access it and they can into the server or the EPIC medical records in any hospital in Maryland, D.C., or northern Virginia through the CRISP network. Doctors have to know to do that, they have to know to click the link, they have to believe the document they see is relevant and meaningful and up to date. Maryland has the data readily available to answer questions regarding their use and so he supports asking the Maryland Health Care Commission for answers to these questions.

Peggy Funk suggested to Jane Markley that they set up a meeting to talk about what specific data the Council might like to see from the Commission. Jane Markley agreed. Jeff Zucker said that the Horizon Foundation has done an amazing job at the grassroots level of trying to raise awareness of at least the importance of naming a health care agent. Because of

Horizon's efforts, he said you are likely to see a greater density of advance directives in the zip code areas marketed to by Horizon. Also, Montgomery County is likely to reflect a higher participation rate because of the efforts to reach the community there. He said if an advance directive has not been reviewed in several years it may no longer reflect the patient's wishes and would not be as reliable.

Jane Markley said that a doctor is only going to spend time looking for an advance directive on CRISP if there is a large number of them available to them there. If they keep looking and nothing is available to them after repeated attempts, they are going to stop looking in CRISP. Christopher Kearney asked Jane Markley if she could volunteer with Peggy Funk and Paul Ballard to track down this information before the next Council meeting. They agreed to do this.

Christopher Kearney gave an update regarding the end-of-life care prisons workgroup and thanked Marian Grant for her strong leadership on this issue. On March 6, 2023, workgroup members met with Dr. Oscar Jerkins who is the medical director for the prison system to discuss the Council's concerns with Maryland's contract for prison health services. Dr. Jerkins shared the Council's concerns about access to, and the quality of current end-of-life services being offered in Maryland prisons, and particularly about care for those incarcerated individuals needing custodial/nursing home care. In lieu of a follow up meeting with the workgroup, he emailed that he found a space in the Hagerstown area where several beds/rooms are intended to be utilized for custodial needs and terminally ill patients who cannot be medically paroled. He said this space could be available by the end of summer. He also directed that Washington County Hospice be contacted to partner for assistance with palliative care and hospice services for these patients and is working on the necessary clearances. He did not respond to the workgroup about Maryland's new contract for prison health services that ends that in December but said a new proposal is being drafted to go out for potential bidders. The workgroup has contacted the procurement officer at the Department of Public Safety and Correctional Services about this proposal. Christopher Kearney said he thinks that the workgroup will have the opportunity to meet with Dr. Jerkins again. The workgroup was disappointed that the cross-filed bills regarding medical and geriatric parole did not pass. Christopher Kearney thought these bills may simply have had less priority in a very busy legislative session.

Peggy Funk added that Dr. Jerkins had asked her to send him some information on some hospice prison programs across the nation. She said there are several such programs that are very well known and do a very good job. She was able to send him information regarding the hospice care program in Angola prison in Louisiana, and programs in Maine, Missouri, and one other state. She was optimistic that Dr. Jerkins was at least willing to consider contracting with a hospice care program, that is, Hospice of Washington County, which is in the area of the Hagerstown prison facility, so that at least some hospice care could be given. Hopefully, now that the 2023 legislative session is over, the workgroup will be able to explore some of these suggestions further with Dr. Jerkins. Christopher noted that at the very least, bringing this attention to the attention of various state agencies had made the Council's work better known to people in Maryland.

Christopher Kearney discussed the National Academy for State Health Policy grant that Maryland applied for, which grant would be very useful to the palliative care workgroup's concurrent investigation of the state of palliative care being conducted under the auspices of the Maryland Health Care Commission at the behest of the General Assembly, in terms of trying to help to improve state of palliative care in Maryland after the workgroup's work is completed. Both the Maryland Health Commission, through Ben Steffen, and the Maryland Department of Health's Medicaid Program, through Tricia Roddy, applied for and obtained the grant. The kick-off call among the grantee states was recently held.

Peggy Funk said this grant is an exciting opportunity for the State of Maryland. She is very proud that Maryland was chosen as one of the six participating states to be chosen for the project. It took a lot of work, and she thanked Marian Grant for all her work on this issue. Peggy Funk said that she, Ben Steffen, Tricia Roddy, and Marian Grant are on the workgroup from Maryland. Peggy Funk explained this grant is called the National Palliative Care State Institute and that this is a two-year program. The next step will be to present a state plan. If Maryland is going to develop a hoped-for palliative care benefit, the plan would describe how Maryland would best go about doing that, as possible examples, through a State Medicaid waiver, through an expansion of Medicaid to get palliative care into Medicaid coverage, or perhaps through the State's Affordable Care Act benefits. At the next meeting they will lay out Maryland's plan with a timeline attached to it and then the Institute will be helping with actuarial services so that they will know what the benefit will look like, what will it include, what it is going to cost, and where that money will come from.

Christopher Kearney said that Marian Grant told him that some states are ahead of Maryland in this area and have some fairly sophisticated state players involved. So, it will be helpful for Ben Steffen and Tricia Roddy to see what some of these states have already done. He believed that the NASHP Institute should be able to play a helpful role in proposing possible ways to pay for a palliative care benefit.

Christopher Kearney updated the council regarding the work of the palliative care workgroup. He said that the survey had been sent out and the responses have been received. They are now reviewing the survey results. The workgroup is required to submit a preliminary report in July of 2023 and the final report is due in November of 2023.

Christopher Kearney next brought up the topic of how the Council might play a role promoting National Healthcare Decisions Day for 2024. Jane Markley said it is a Herculean effort to put together a program with an all-volunteer staff. She and her colleagues had just completed the end-of-life program for National Health Care Decisions Day which had been put on by the Montgomery County Palliative Care and End-of-Life Coalition, which coalition has become very active in Montgomery County recently. She asked whether the Council had been successful in 2023 in getting the Governor to do anything in promotion of the Day. No one had seen anything from the Governor's Office regarding the Day. Jane Markley said the Council is in a position help effect that and to get it more visible on a senior level within the State of Maryland.

Jack Schwartz suggested that given how many years that National Health Care Decisions Day has been observed in the country, perhaps there are studies about what efforts have actually been successful. He thought there must be some best practices that have been developed. Jane Markley said there are a lot of people who have those kinds of data points. Jeff Zucker said he would be happy to provide such data. He said that people who promote the use of advance directives should lead by example. He said that if each of the Council members has an advance directive, ensures that it is updated and current, and that they have uploaded it so that it is accessible through CRISP so that it can be found, the Council members would be demonstrating best practices.

Peggy Funk complimented Jane Markley's presentation she recently made at the webinar that the Montgomery County Coalition presented in honor of National Healthcare Decisions Day. At the webinar they focused on the distinction between an advance directive and a MOLST form because so many people are confused about these documents. They had 200 people sign up for the webinar and 135 people attended. Not just the public, but many nurses and social workers who were being offered continuing education credits by the Hospice and Palliative Care Network were also confused about the difference between an advance directive and a MOLST form. She wondered how we can expect the general public to understand these documents if health care providers can't even explain to them how to complete and upload them, so they are accessible on CRISP. So, maybe it isn't just the general public that needs this information, but also health care professionals. Jane Markley agreed. Jeff Zucker echoed these concerns about the lack of understanding among even health care professionals, noting that 40% of nurses mix up the terms "palliative care" and "hospice care." Christopher Kearney asked Jane Markley if she could make at least part of her National Healthcare Day presentation to the Council at a future meeting. She agreed to do so.

Jeff Zucker raised general concerns about the Maryland MOLST form and Peggy Funk wondered whether the Council should revisit some of the provisions and examine whether certain changes should be made. Christopher Kearney thought that that this issue was a challenging one and should be tabled for later discussion.

Christopher Kearney stated that replacement of vacancies on the Council has been a bit of a challenge because of the transition to a new administration. Paul Ballard said he was going to meet with a representative from the Governor's Appointments Office regarding the issue.

Christopher Kearney discussed the possibility of having an in-person Council meeting perhaps once a year. He also suggested scheduling the Council meeting for one hour in length. Paul Ballard stated his thought that with a presentation that 1 and ½ hours works better but if there is no presentation that one hour would be a sufficient length for the meeting. Jane Markley said it would be better to schedule the meeting for 2 hours in case that time is needed and to try to get the meeting over with in less time if possible. Christopher Kearney said the Council will try to schedule the next meeting for an hour and see what happens.

Christopher Kearney said the Council's charter is to monitor trends for the provision end-of-life care in the State of Maryland and to study the impact of State statutes, regulations, and policies, and he thinks in many ways the Council is doing this such as in being involved in the

palliative care workgroup and working with the legislature. Regarding the Council's authorizing statute's third mission statement of providing recommendations to State agencies, he does not know how much the Council has done that in the past, but they were fortunate this year to talk with the Secretary of Health who is very proactive and sensitive and aware of serious illness and end-of-life care. Perhaps the Council should make a standing report annually to her about what the Council is concerned about, and perhaps the Council should do the same with the Secretary of Aging so that they can update them. He thought that would help the Council fulfill its role of providing recommendations to the Department of Health and the Department of Aging, and other State agencies. He hoped that in the coming year the Council might focus more of its attention on monitoring trends for the provision of end-of-life care in Maryland and making recommendations to State agencies.

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