

**State Advisory Council on Quality Care at the End of Life  
Minutes from the October 18, 2017 Meeting**

**Meeting time and place:** October 18, 2017, 10:00 a.m., Office of Health Care Quality, 55 Wade Avenue, Spring Grove Hospital Center, Bland Bryant Building, Catonsville, Maryland.

**Council members present:** Alan Eason, Chair; Paul Ballard (Attorney General's designee); Sister Lawrence Mary Pocock; Stevanne Ellis (Department of Aging's designee); M. Jane Markley; Hank Willner; Rabbi Steve Glazer; Hung Davis; Linnette Rivera (Department of Disabilities' designee); Elena S. Boisvert; Christopher D. Kearney; Marian Grant; Lya Karm, Tiffany Callender; Tricia Nay (Department of Health's designee); Carol Eckerl.

**On speakerphone:** Gail Amalia Katz; Donald D'Aquila; Jocelyn El-Sayed.

**Others present:** Gail S. Mansell; Joshua Jackson; Molly Cook; Jennifer Briemann; Michelle Miller; Rebecca Daley.

Chairman Alan Eason convened the meeting at 10 am.

Prior to the meeting, all Council members were asked to talk about their backgrounds, what they believe is working well in end-of-life care, what they believe could be improved in end-of-life care, and what role they believe that the Council might play in helping to improve end-of life care.

Alan Eason stated that he had worked for 30 years as an Assistant Attorney General in the Maryland Office of the Attorney General prior to retiring in 2010. He has been auditing health care law classes at the University of Maryland School of Law. He is also a Certified Master MOLST Trainer. He has in the past volunteered with Compassion and Choices and still believes in their efforts, but finds that providing education on advance directives and health care is more engaging. He stated his belief that autonomy is very important in health care and that hospice and palliative care need to be promoted.

Carol Eckerl works as a social worker and her passion lies in chairing an ethics committee. She believes that we need to improve health care conversations and make sure patients understand the choices they make.

M. Jane Markley worked as a nurse prior to her retirement from the Navy. She is currently a member of a facility's ethics committee. She is now engaged in consulting on advance care planning doing 1:1 work with individuals and their families and speaking on advance care planning locally, nationally, and internationally. She helps to facilitate how medical students can communicate better on end of life issues at the Uniformed Services University of the Health Services at Bethesda, MD. She continues to work with the Montgomery County Coalition on Care at the EOL which is re-focusing its efforts on Community based Palliative Care. She believes that one major challenge is that there are a huge number of people who don't understand the difference between advance directives and the MOLST form. Physicians don't understand the MOLST form and that should be a focus of the Council.

Steve Glazer is a retired rabbi who serves on various ethics committees. He is a bioethicist and has a strong interest in patient autonomy.

Hung Davis said his first job as a physician was as a hospitalist. In 2007, he started a company to start hospitalist programs covering hospitals and nursing homes. He is the Chief Medical Officer for an acute rehabilitation facility. He believes it is important to do a better job in communicating with patients regarding quality of life issues and that it is also important to persuade hospitals to complete page 2 of the MOLST form.

Hank Wilner is interested in informed consent. He would like to see palliative care introduced more widely. He believes palliative care needs to be taught in medical schools. He would also like to see the terminology of Do Not Resuscitate changed to Allow Natural Death.

Linnette Rivera said she has been a health care agent for relatives. She believes we need to be cognizant of people's mental status at the end of life.

Stevanne Ellis is a social worker and was a local ombudsman for 8 years. Now she is a State ombudsman. She said there are lots of personal issues involved with end of life care. She believes more conversations are needed about what people want at the end of life and about things that are not written about, such as the use of antipsychotic medications. She stated that there are situations not covered by advance directives or the MOLST form. She also expressed the concern that hospice care is usually opted for way too late, often just days before death.

Elena Boivert is an attorney and a volunteer ombudsman. She is concerned about where patients are getting care and believes there is a bias in favor of delivering care exclusively in nursing homes. She believes that the Medicaid Waiver program is important and noted that Maryland capped the budget for the Waiver program that would have allowed more people to get care at home or in an assisted living program rather than in a nursing home. Stevanne Ellis noted that the waiting list is for people at home now and not for folks already in a nursing home, the latter of which take priority.

Sister Mary Lawrence Pocock has been a nurse since 1965. She has worked with the elderly and the very poor. She said that in their nursing home there is one resident who is 105 years old who has been in the home for 40 years. She said their nursing facility is like a home. She stated that conversations should begin sooner. She noted that at their nursing home that they speak to the residents often about their choices. They do their best to make the dying process as comfortable as possible.

Christopher Kearney has been on an ethics committee. He is the palliative care medical director for Medstar hospital system. He has been involved in thousands of meetings with families. He stated that early conversations are good. He noted that in Baltimore there are very few advance directives. He said that hospitals are not incentivized to have these conversations. He stated that there are a growing number of ICU beds and noted that an ICU is not an ideal place to have these conversations. He stated that there is pressure to get patients out the door. He believes that Maryland could be a leader in a pilot project in palliative care/hospice programs.

Marian Grant is an associate professor at the University of Maryland Medical School. She represents an advocacy group interested in addressing all issues of advanced illness. She has been involved in federal legislation to promote advance care planning. She noted that 22 states have councils like the State Advisory Council on Quality Care at the End of Life. She believes a big barrier is the lack of payment for advance care planning and care in the home. She stated that people want shared decision making.

Lya Karm is a retired physician from Kaiser Permanente. She stated she spent the last 5 years working in palliative care. Fortunately, in that setting payment was not an issue. She stated that palliative care teams are needed and noted that unfortunately there are still people with end-stage conditions on a ventilator with no conversation having taken place regarding their wishes.

Tiffany Callender works for the Horizon Foundation Endowment. She said this program helps to promote advance care planning. She is a social worker and noted that the culture is changing on this issue and that there are more documentaries about advance care planning. She agreed with Linette Rivera's point about older adults and their mental health issues. She believes there is an opportunity to reach out to minorities regarding the promotion of advance directives, and to promote advance care planning through the use of hospice video advertisements, cable advertisements, and the like. She said that the Horizon Foundation has been involved in a very big public relations program in Howard County to promote advance care planning.

Tricia Nay is a hospice physician and Executive Director of the Office of Health Care Quality. She has responded to many MOLST inquiries and has seen the quality of the questions she has received improve over the years, showing that the understanding of the MOLST form among health care providers has improved, although the knowledge shown has been uneven.

Gail Amalia Katz is a retired administrator in the area of oncology. She has made health care decisions on behalf of her relatives. She stated it took more than a generation to change the way we give birth to children. She stated her belief that the greatest benefit the Council can provide is education.

Donald D'Aquila is a pharmacist trained in the principles of palliative care and hospice. He has been a consultant for United Healthcare. He stated his belief that there is a need for improving the public's perception of hospice care and palliative care for getting people to be admitted into hospice earlier and to use palliative care options earlier, and to improve advance care planning conversations. He stated that more specialty training is needed in palliative care. He stated there is also a need for greater access to hospice and palliative care services in rural areas such as on the Eastern Shore. He said an important issue is how we can improve our symptom management and bring down the costs of medications used in hospice programs.

Paul Ballard read from an email sent by Michele Williams in which she stated she has been working in the specialty of oncology and palliative care since 1991. She is an Oncology/Palliative Care Nurse Practitioner for University of Maryland Regional Care Center Shore Regional Cancer Center in Easton MD. She is an Associate Medical Director for Talbot Hospice in Easton MD and she recently implemented a Lung Cancer Screening Program for

University of Maryland Shore Regional Cancer Center, which is serving patients in 5 counties and 3 hospitals.

Michele Williams wrote that what she believed was working well in end-of-life care has been an expansion of palliative care services at all hospitals with greater than 50 beds and that this has led to earlier referrals to hospice and improved symptom management for end of life care. She wrote that what could be improved in end-of-life care was to provide high-quality care that is consistent with patients' preferences, to have advanced care planning and goals of care conversations with patients and families done earlier rather than later. She also wrote that what was needed was to train more clinicians in palliative care. Finally, she wrote that the Council should participate in both public and professional efforts to promote quality care at the end of life, that the Council should be up-to-date on current trends, and should promote early advance care planning and goals of care conversations.

Paul Ballard stated that although the MOLST law and the education efforts arising from it have heightened awareness of the laws regarding health care decision making, there are still great gaps in the knowledge of these laws among health care providers and the public.

Paul Ballard explained what the Council's statutory mission is, talked about the Council's website, and distributed a chart of discussion items at past Council meetings that had been prepared by Steve Levenson, former Council member.

Paul Ballard discussed some of the legislation enacted in the 2017 session of the Maryland General Assembly. House Bill 498 was enacted into law, which made changes to the Health Care Decisions Act regarding who is eligible to make health care decisions for a patient. The changes include: (1) A person who is the subject of a protective order under which the patient is eligible for relief may neither serve as a health care agent nor as a surrogate decision maker; (2) Under most circumstances a patient's spouse may not act as the patient's health care agent under an advance directive if a patient and their spouse entered into a separation agreement or if one of the spouses filed for divorce (an exception exists when the patient expressed the intent to have the spouse serve as a health care agent anyway); and (3) A spouse may not act as a surrogate decision maker if one of the spouses filed for divorce or if the patient and the spouse entered into a separation agreement.

Paul Ballard stated that House Bill 188 was enacted into law, which made some clarifying changes to the provision in the Health Care Decisions Act regarding the valid execution of electronic advance directives, authorized the Maryland Health Care Commission to contract with multiple electronic advance directives services to connect with health care providers at the point of care through the State-designated health information exchange, and provided for funding of the Department's advance directive program.

Finally, Paul Ballard updated the Council on the MOLST form's pending changes. He explained that the changes have been stalled because of a hold placed on regulations by the Governor while the Regulatory Reform Commission conducts its third year of work. The proposed changes have been approved and reviewed by all the entities required by law to do so

prior to publication in the Maryland Register. The proposed changes are the same changes previously reviewed by the Council in its prior meetings.

No further items of business being presented, Chairman Eason adjourned the meeting.