

**State Advisory Council on Quality Care at the End of Life
Minutes from the September 18, 2014 Meeting**

Meeting time and place: September 18, 2014, 10:00 a.m., Department of Aging, 301 West Preston Street, Baltimore, Maryland.

Council members present: Ted Meyerson, Chair; Paul Ballard (Attorney General's designee); Donna Leister; Rabbi Michael Safra; Marian Grant; Sister Lawrence Mary Pocock; Gail S. Mansell; Tom Smith; Hank Wilner; Donna DeLano Neuworth (Department of Aging's designee); Lya Karm; Gail Amalia B. Katz. On speakerphone: Karren Pope-Onwukwe; Mary Lynn McPherson; Tricia Nay (Department of Health and Mental Hygiene's designee).

Others present: LaWanda Edwards (on behalf of Senator Manno); Elena Boisvert (on behalf of Catherine Stavely); Yvette Rode; Sally Hunt; Alan Eason.

Chairman Ted Meyerson convened the meeting at 10:00 a.m.

Ted Meyerson discussed the Associated Press article regarding the Institute of Medicine's report "Dying in America." The report concluded that the medical system is ineffective in giving people the care they want to receive, noting such problems as perverse financial incentives caused by the fee-for-service payment system that rewards more aggressive treatments, inadequate training of medical staff in end-of-life care, and physicians' worries about liability if they do not provide life-saving treatments. Ted Meyerson noted that the Council's efforts to educate the public about these issues are hampered by its inability to raise money and handle funds that could be used to educate the public on these issues.

Paul Ballard stated that the Office of Health Care Quality awarded a grant to the University of Maryland to study the implementation of the Medical Orders for Life-Sustaining Treatment (MOLST) form. The study will show how the MOLST form is being used in hospitals, nursing home, assisted living programs, hospices, home health care agencies, and kidney dialysis centers. The results of the study will be useful in helping to determine how the MOLST form is being used in these health care settings.

Paul Ballard updated the Council on the Advance Directive Registry. The Maryland Health Care Commission has worked with CRISP to put an advance directive registry on the State-designated Health Information Exchange. People have been preparing electronic advance directives on the HIE. The Health Care Commission hopes to put MOLST forms on the HIE by late 2015. The advance directive registry on the HIE does not match the statutory requirements for a State advance directive registry. Specifically, the legal issue is created by the existence of § 5-625 of the Health-General Article which reads: "Before accepting an advance directive into the Registry, the Department shall review and verify that the advance directive includes: (1) The signature of the declarant; (2) The date on which the advance directive was signed by the declarant; and (3) The signature of two witnesses as provided in § 5-602(c) of this subtitle." Thus, if an advance directive does not have the signature of two witnesses, the Department is not authorized to accept the advance directive into the Registry. To do so, either the registry on the

HIE will need to be changed or the statute will need to be amended. Council members asked Paul Ballard to clarify whether an existing advance directive could be placed on the registry.

Regarding educational campaigns regarding advance directives, Ted Meyerson showed the Council the prepareforyourcare.org website as a possible educational tool to promote the preparation of advance directives. The website is interactive and provides text, videos, and choices that the user can make in preparing an advance directive. The Council agreed that it was a helpful website. Tom Smith stated that the Kaiser Permanente videos are used by Johns Hopkins and have been very helpful in helping patients make decisions about their health care. While 80% of patients want CPR before watching the video, only 20% want CPR after watching the video. He noted that physicians who are medical residents at Hopkins will soon be required to view the video. Ted Meyerson also showed the Council a color sheet describing how to access the advance directive and MOLST videos on YouTube. Some Council members volunteered to make the links available at their health care facilities.

Hank Wilner discussed the issue of medical ineffectiveness. He suggested that the definition in the Health Care Decisions Act should be more oriented towards whether a treatment is non-beneficial rather than whether it is ineffective. For example, he noted that a health care provider may view CPR to be futile for a certain patient but the family will instead be focused on keeping the patient alive without consideration of whether CPR will provide any benefit to the patient. He suggested that perhaps a new definition could be used that would focus on whether a certain treatment was beneficial to patient, would prolong suffering, would improve the quality of life for the patient, or otherwise promote the patient's meaningful goals of care.

Tom Smith noted that no matter what the treatment is called there will be family members who will still insist on care that might be medically futile, and sometimes family members just need to be told that the patient is dying in order for them to grasp the concept that the treatment is medically ineffective. Donna Leister noted that the terminology "prolong suffering" may be more persuasive for family members than the terminology "medically ineffective." Paul Ballard stated that the statutory definition of medical ineffectiveness is really designed to limit those instances where a physician may determine that a life-sustaining treatment should not be given despite the wishes of the patient or the family. Hank Wilner suggested that there should a checklist of goals of care for every patient in an intensive care unit.

Ted Meyerson discussed the possibility of creating some sort of a State Unit under the Council's control that would allow the Council to raise and handle funds to promote educational projects and research. Council members supported the concept but agreed that such a proposal would require thorough planning and extensive discussions with legislators.

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