

**State Advisory Council on Quality Care at the End of Life
Minutes from October 23, 2009 Meeting**

Meeting time and place: October 23, 2009, 10:00 a.m., in the Department of Aging's Conference Room, 301 West Preston Street, Room 1007.

Council members present: Catherine Boyne, Chair; Timothy Keay; Gail Mansell; Melinda Sauders; Ted Meyerson; Karen Kaufman; Steve Levenson; Mike LaChance (Secretary of Aging's designee); Paul Ballard (Attorney General's designee); Cari Watrous (Secretary of Disabilities' designee); Gloria Ramsey (via speakerphone).

Others present: Jim DeBoy

Catherine Boyne convened the meeting at 10:00 AM and welcomed Council members and guests.

Paul Ballard provided the Council with a letter from the Food and Drug Administration that responded to the Council's letter expressing the Council's concerns regarding severe shortages of certain opioids used to relieve pain for patients. These drug shortages make it difficult for health care providers to relieve the pain of terminally ill patients. The FDA stated it was aware of the shortages of oxycodone tablets, oxycodone oral solution, and morphine concentrated solution and informed the Council that the oral tablet shortage had been resolved. The manufacturers of the oral solution and morphine concentrated solution were working to increase supplies.

Mr. Ballard noted that the wallet cards regarding advance directives were placed on the Attorney General's website and thanked Council members for their input.

Mr. Ballard discussed the House Bill 30 workgroup. He noted the discussions have been productive. Maryland Medicine, a magazine published by Med Chi, will put out a special issue devoted to hospice and palliative care and other topics relating to end of life care. There is general agreement among the workgroup on the need for education to providers on how to have these discussions, education to patients so that they are made aware of the need to ask for these discussions, and that financial disincentives exist for referrals of nursing home patients to hospice because of the "pass through" billing arrangement required by Medicare. Mr. Ballard provided the Council with the workgroup's draft report, which is primarily concerned with statistics related to hospice care given the greater availability of information regarding that care versus palliative care.

The workgroup is discussing recommendations, including a Patient End of Life Bill of Rights. The thought behind the proposed Bill of Rights is to raise public awareness regarding expectations for services at the end of life. Mr. Ballard distributed to the Council a copy of the National Framework and Preferred Practices for Palliative and Hospice Care Quality which he has suggested to the workgroup as a model. Ms. Boyne believed this document would provide a good framework for a Bill of Rights. Ted Meyerson stated that he suggested to the workgroup that education about end of life care

should begin as early as high school. Mr. Meyerson rejected the idea that the Council should work on the Bill of Rights because the diversity of interests represented on the workgroup should be sufficient to arrive at a satisfactory Bill of Rights. He further stated that the Bill of Rights should be given out at all health care facilities and physicians' offices.

Steve Levenson stated that perfectly good end of life care may be given through providing palliative care without involving hospice and indeed that in his experience hospice care is sometimes not effectively provided in nursing homes by hospices. Dr. Levenson further noted that oversight of hospices is not included in the draft report and there should be more emphasis on the palliative care process rather than so much emphasis on hospice. Mr. Meyerson also noted that the workgroup's Bill of Rights should include a patient's right to not to receive any treatment in addition to the options of receiving palliative care or hospice care.

The Council discussed Senate Bill 221 from the 2009 legislative session, which passed in the Senate but did not pass in the House of Delegates. Senate Bill 221 would have required a health care facility to disclose its policies regarding the implementation of advance directives and requiring the health care facility to ask a patient whether the patient had an advance directive. The Council thought that the amendment to the bill requiring all patients, regardless of their condition, be provided with the local hospice's phone number, was overbroad. It was noted that the Joint Commission has an existing standard requiring facilities to honor advance directives, which standards would apply to hospitals. Dr. Levenson noted that the critical point is whether a hospital enforces this policy when a particular practitioner ignores or refuses to enforce an advance directive. Mr. Ballard noted that nursing home regulations already have pretty strong regulations regarding disclosure to the patient of their right to prepare an advance directive. Dr. Levenson stated that the bill would really just require health care facilities to follow the existing laws, although Mr. Ballard noted that at present there is no requirement that facilities disclose to patients their policies regarding the implementation and enforcement of advance directives.

The Council discussed the issue of whether a certified nurse practitioner should be allowed to certify that a patient is incapable of making health care decisions and that the patient is in a terminal condition or an end-stage condition. There was no resolution of the issue and the Council has no recommendation at this time.

Dr. Levenson submitted to the Council his workgroup's report on POLST (Physician's Orders for Life-Sustaining Treatments). The report concluded that POLST is better at getting practitioners to implement patient's wishes than just having an advance directive. Nursing homes appear to be the only type of facility reliably complying with the Health Care Decisions Act because of greater enforcement efforts. POLST is better at ensuring compliance with the Health Care Decisions Act, although POLST does not guarantee compliance in all cases. The workgroup believes that the Current Life-Sustaining Treatment Options form ("LST Options form") could be used as the basis for a POLST form, the critical difference being that unlike an LST Options form, a POLST form would

be a physician's order. The workgroup recommended that offering the LST Options form should be required in health care facilities other than just nursing homes as is current law. The workgroup will next look into whether the POLST form could be combined with the EMS/DNR order issued by the Maryland Institute for Emergency Medical Services Systems. The workgroup will consult with Dr. Patricia Nay at the Office of Health Care Quality.

Gloria Ramsey reported for her workgroup on racial disparities. Dr. Ramsey reported that the workgroup is looking at data and consulting with persons from around the State regarding how to improve access and awareness for all ethnic groups regarding palliative and hospice care. She noted that the work of the House Bill 30 should dovetail with her workgroup's effort and should inform their efforts.

Ms. Boyne reported that the workgroup looking at pediatric issues have done some interviewing of pediatric hospice and palliative care programs around the nation, that everyone seems to want to do something but are not sure what as yet because they are not sure yet what the population is. She noted that a program in Cleveland seems to fit with Maryland's situation. The workgroup is trying to come up with recommendations that will fit Maryland and are looking at what the present situation is for pediatric palliative care in Maryland. She also noted that there is a federal bill in the legislative process that would provide for pediatric palliative care.

Mr. Ballard gave an update on Council membership. Melinda Sauders was appointed to the Council to fill the position designated for a nurse with experience managing long term care. There is a religious position vacancy, a managed care organization vacancy, a health insurance industry vacancy, and a nursing home industry vacancy.

Mr. Ballard noted that the LST Options form has been translated into Spanish and is available on the Attorney General's website.

The following meetings were scheduled for 2010: January 22, February 26, and June 11. Scheduling of the meeting for the Fall of 2010 was deferred until the next meeting.

No further items of business having been presented, Ms. Boyne adjourned the meeting at noon.