

**State Advisory Council on Quality Care at the End of Life  
Minutes from March 7, 2011 Meeting**

**Meeting time and place:** March 7, 2011, 10:00 a.m., Department of Aging, 301 West Preston Street, Room 1007.

**Council members present:** Ted Meyerson, Chair; Melinda Sauders; Gail Amalia Katz; Hope Kirk; Catherine Stavely; Timothy Keay; Paul Ballard (Attorney General's designee); George Failla (Secretary of Disabilities' designee); Michael McHale; Michael Safra; Karen Kauffman (via speakerphone).

**Others Present:** Alice Hedt; Robbyn McIntosh; Donna Leister; Lya Karm; Hope Kirk; Tricia Nay; Arash Khoie.

Paul Ballard provided the Council with an article he had been given by Tricia Nay regarding a study that showed the emotional toll on substitute decision makers that can result from making decisions regarding life-sustaining treatments without guidance from the patient either through an advance directives or prior conversations.

While awaiting the arrival of Ted Meyerson, Paul Ballard reported to the Council regarding the progress of House Bill 82 and Senate Bill 203 in the General Assembly. These bills were endorsed by the Council and would create a standard "Medical Orders for Life-Sustaining Treatment" (MOLST) form containing orders regarding life-sustaining treatments. The MOLST form would be required to be used in hospitals, nursing homes, assisted living programs, home health agencies, hospices, and kidney dialysis centers, and must be honored by other health care providers to the extent required under the Health Care Decisions Act. The MOLST form would travel with patients transferring between facilities. House Bill 82 passed the House with amendments and the Senate Finance Committee approved the cross-filed Senate Bill 203 with the same amendments.

The amendments consisted of requiring that a patient be informed that the MOLST form would be part of their medical records and could be accessed through the procedures used to access a medical record, requiring that the patient be given a copy of the MOLST form within 48 hours or sooner if transferred or discharged, and requiring that when a patient or decision maker declined to participate in the completion of the MOLST form that there be a note written in the medical record regarding with whom the form was discussed and the date of the discussion. The amendments required a health care provider to honor the request of a patient or decision maker to give their physician or nurse practitioner the opportunity to participate in the completion of the MOLST form. The amendments required that the form's instructions include how the MOLST form would be revised or revoked. The amendments also required that the form and instructions be made available on the Department's web site and authorized the Department to print and distribute training materials.

The bills were also amended to only require hospitals to complete a MOLST form for a patient who would transfer to another hospital or to a nursing home, assisted living program, home health agency, hospice, or kidney dialysis center. In addition, the bills were amended to require that the Department of Health and Mental Hygiene revise the MOLST form periodically. Finally, the bills were amended to allow for a transition period in which nursing homes and assisted living programs would have until April 1, 2012 to complete MOLST forms for residents who were residing in the nursing home or assisted living program as of October 1, 2011. Mr. Ballard stated his opinion that the amendments did not impact the primary purpose of the bill, namely to create a standard and portable order form regarding life-sustaining treatments that would hopefully increase the rates of compliance with patient's wishes for their care at the end of life.

Dr. Nay stated that the Department of Health and Mental Hygiene, the Office of the Attorney General, the Medical Institute for Emergency Medical Services Systems are putting together a Train the Trainer Task Force made up of 50 or 60 representatives of various stakeholders to meet from March through May to finalize the MOLST form, instructions, and training materials. These training materials will include PowerPoint presentations, user guides for health care providers, patients, and substitute decision makers, as well as flyers and information sheets. DHMH, OAG, and MIEMSS representatives will then conduct train the trainer sessions. The stakeholders will then in turn conduct their own training sessions.

Dr. Nay updated the Council on the efforts of the Chesapeake Regional Information System for Our patients (CRISP) to create a pilot electronic registry that will hold advance directives and potentially MOLST forms. CRISP has obtained a \$1.6 million grant to create a pilot program over 3 years that will cover some selected nursing homes. Dr. Nay noted that the MOLST bills authorize the use of an electronic copy of a MOLST form. Dr. Key stated his concern that private registries may need regulatory oversight.

Mr. Meyerson distributed educational cards describing a patient's rights and options for care at the end of life. He noted that the purpose of the cards is to precipitate a conversation between a patient and the practitioner about end of life care. He proposed giving them to a group of doctors to try them out in their offices to see what responses they might get from patients. If the physicians reported good responses from patients, then the Council could raise money to print and distribute the cards to health care providers throughout the state. Dr. Nay suggested that Med Chi and the Board of Physicians could provide them to physicians who request them.

Mr. Meyerson noted the importance of having some standard way to measure the feedback from practitioners regarding the cards. Dr. Key suggested the appropriate test might be whether it had precipitated conversations with their patients regarding end of life care. Dr. Nay suggested that one measurement might be how many cards were taken by patients. Council members suggested different practitioners who could participate. Dr. Nay suggested that Council members send Mr. Ballard contact information for these practitioners

Mr. Ballard asked the Council members to review a chart of laws supporting the patient's rights discussed in the educational materials prepared for the educational campaign. He asked the Council to review whether the chart should be included on the Council's website. The Council agreed that the chart should be placed on the Council's website.

Mr. Meyerson stated that there seems to be a movement away from promoting advance directives. Timothy Keay noted there was great hope for the effectiveness of living wills when they were first created but instead they have become mainly aspirational documents. This has prompted the move towards more actionable documents such as the MOLST form. Mr. Meyerson asked whether it might be better to emphasize the MOLST form rather than advance directives. Dr. Keay noted the value of advance directives in helping families deal with the decisions made by the patient. Dr. Nay noted that the most important part of the process was the conversation between the patient and the practitioner. Dr. Keay agreed that emphasis on these conversations is preferable to simply filling out an advance directive in the absence of such conversations. Rabbi Michael Safra noted that from a pastoral perspective it would be easier for substitute decision makers to know what a patient would want contained in a MOLST order if an advance directive had been prepared by the patient.

Karen Kauffman raised the issue as to whether the MOLST form's instructions should include a statement that some health care providers may decline to carry out orders contained in the MOLST form based on the provisions in the Health Care Decisions Act that permit them to decline to refuse to provide care they deem to be ethically inappropriate. The Health Care Decisions Act also requires a health care provider to notify the patient and decision makers of their intent not to comply with the orders and to assist them with transfer to another health care provider. Ms. Kauffman believed it was important that persons be informed of the limitations of these orders because there is a common misperception that advance directives must always be honored by health care providers.

No further items of business having been presented, Mr. Meyerson adjourned the meeting at noon.