

**State Advisory Council on Quality Care at the End of Life  
Minutes from the September 14, 2012 Meeting**

**Meeting time and place:** September 14, 2012, 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); Gail Amalia Katz; Alice Hedt (Department of Aging's designee); Thomas Smith; Donna Leister; Delegate Dan Morhaim; Senator Roger Manno (via speakerphone); Catherine Stavely (via speakerphone) Lya Karm; George Failla (Department of Disabilities' designee).

**Others present:** Timothy Keay; Tricia Tomsko Nay; Leslie Piet; Steve Clarke; Barbara Biedrzycki, Kathleen Todd.

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

The Council discussed the Allow Natural Death form presented by Delegate Morhaim who stated that many hospitals around the country have replaced the term "Do Not Resuscitate" with "Allow Natural Death." LifeBridge Health/Sinai Hospital ("Sinai") has replaced its internal Do Not Resuscitate forms with Allow Natural Death forms. He explained that the "Allow Natural Death" terminology is more consumer-friendly because "Do Not Resuscitate" has the connotation that a treatment the patient might want is being withheld. Delegate Morhaim wrote a letter to Ted Meyerson, Paul Ballard, and Robert Bass of MIEMSS asking that the Council and MIEMSS consider this topic and take steps to replace "Do Not Resuscitate" ("DNR") with "Allow Natural Death." MIEMSS wanted the Council to review the issue and make recommendations. The Council reviewed Sinai's order form containing the term "Allow Natural Death."

Ted Meyerson asked what would be involved legislatively. Delegate Morhaim said the first step would be for the Council to decide whether it would make sense to change the terminology. If so, he would talk with stakeholders and explore the possibility of introducing legislation if needed. Ted Meyerson asked how it would relate to the Medical Orders for Life-Sustaining Treatment (MOLST) form. Delegate Morhaim said it would change the CPR portion of the MOLST form. Tricia Nay said that should there be any changes to the form that MIEMSS recognizes, i.e., the MOLST form, they would be included in the next revision of the MOLST form when the medics would be trained in use of the new form. She stated that when MOLST was developed, this issue was discussed but the consensus developed to leave DNR as it was at that point because there were many other issues involved then. Delegate Morhaim said that "Allow Natural Death" is a much better accepted term by the public than DNR and if the Council agrees we can move forward with a process to make the change, which may take some time. He said the term "Allow Natural Death" saves a patient from anxiety and confusion. Delegate Morhaim said that Sinai did a lot of vetting of the order form internally before implementing it and that the form has worked very well for them.

Donna Leister noted that the term "Allow Natural Death" is kind and compassionate and communicates that support is not being withdrawn. Gail Amalia Katz thought "Allow Natural

Death” was gentler terminology but that we should be careful to insure it is not misunderstood. Tricia Nay said that one of the reasons that MOLST form does not have the term “do not attempt resuscitation” was because it was felt that the average person on the street understood the term “do not resuscitate” better than terms such as “do not attempt resuscitation” “no code,” “Allow Natural Death,” or other terms. She noted that the public has already been educated on the meaning of “do not resuscitate.” Delegate Morhaim said that the need to educate people should not prevent the change to “Allow Natural Death” if that is a better term. Delegate Morhaim noted that he wanted to wait to do this until after MOLST was finalized before initiating this change.

Leslie Piet asked if Sinai’s form was developed by a palliative care team or by a wider group of practitioners and Delegate Morhaim responded that it was developed by a wide group of practitioners. He noted that it was implemented after a year’s worth of work with the input of many different types of practitioners and others, including patients. Timothy Keay remembered that as a medical student that “Allow Natural death” meant not to do anything. He thought this was a good first step but that the form must be made be clear that “Allow Natural Death” does not mean the withdrawal of treatment and that the form should reflect that full support appropriate to the patient’s condition will be given. Senator Manno suggested that the use of the term “appropriate” might be problematic from a liability perspective if clarity is not given to the meaning of that term and thought that “do not resuscitate” was clear.

Tricia Nay stated that any of the terms “do not resuscitate, “do not resuscitate“ and “Allow Natural Death” can all be made clear within a health care system. She noted that transitions to new terms require education. Tom Smith thought that both terms “do not resuscitate” or “Allow Natural Death” work in practice but that it is critical to assure patients and family members that under either term that care is not being withdrawn, and to explain that even though life support is not being provided that care will continued to be provided, probably even more intensely than before. To clarify this, he suggested that perhaps the form should say “full resuscitation” rather than “full support” to distinguish the concepts and to instead use the term “full support” with the term “Allow Natural Death.” He asked whether Sinai’s form has met people’s expectations and whether it has increased the frequency in which these discussions are held. Delegate Morhaim’s understanding was that it did have these positive results because no one had offered any complaints about the form.

Timothy Keay suggested “allow natural death with comfort.” Alice Hedt said that she loves the term “Allow Natural Death” as it shifts the discussion in the mind of the consumer to what is a natural process. She also noted that it would need clarification because the term can often also be taken to mean not providing other treatments such as artificial nutrition and hydration. Tricia Nay has also seen the term used in a broader fashion than just being applied to CPR and thus noted that it is critical how you define the term.

Senator Manno asked Paul Ballard whether the term would be clear to providers. Mr. Ballard said if the Council decided to move forward with changing the term “do not resuscitate” to “Allow Natural Death,” that the MIEMSS statute regarding “do not resuscitate” would probably have to be amended. George Failla noted that the form should clarify that “Allow

Natural death” only addresses CPR and does not cover other treatment decisions, for example, such as whether to receive artificial hydration.

Lya Karm suggested reviewing studies regarding the use of the term “allow natural death” and people’s reactions to it before making a decision about this issue. Tom Smith noted that he had seen some studies on the issue and agreed to do a literature search and to send articles to the Council. Ted Meyerson asked that proposals on the issue be discussed at the next meeting.

Ted Meyerson then discussed the education of health care providers on how to talk to patients regarding end-of-life issues and the education of patients on how to talk to health care providers on these issues. He had hoped that the United Seniors Foundation could put together an educational program but reported that the Foundation decided it did not have the resources to support such a program at this time. Delegate Morhaim said that medical schools could present these programs. Tom Smith said that at Johns Hopkins 3<sup>rd</sup> year medical students are trained with actors telling patients about terminal illness. They had just done that recently for the first time with oncology students. He said they are trying to standardize the training and not just restrict it to discussions with cancer patients. He said that physicians under 35 years old have gotten substantial training in having these discussions but physicians over that age probably have not received such training. Timothy Key noted that at University of Maryland there is required training regarding these issues and having these discussions with patients and families. Tricia Nay noted that she is seeing code status and advance directive issues addressed in patients’ charts by younger physicians. Leslie Piet noted that nurses are receiving training in end-of-life issues.

Ted Meyerson asked whether, assuming that health care professionals are being educated, the Council wanted to try educational programs for patients and family members on how to have discussions with physicians. Tricia Nay suggested that perhaps the Council could support the educational programs that exist currently without having to create a new program. Tom Smith stated that MOLST should help open up the conversation and noted that continuing education requirements for physicians on the topic of end-of life conversations have not helped much where they have been tried. Ted Meyerson said that if you can have a standard script that could be followed, then the training could be done by anyone. Tricia Nay stated that you need to develop a presentation appropriate for the target audience based on their level of sophistication and what they specifically need to know. Therefore, it is very hard to standardize the program.

Alice Hedt said that the ombudsmen have been taking the MOLST form out to nursing homes and assisted living programs to make sure that patients and families are aware of the form. She thought that a standard presentation about MOLST targeted to patients and families that could be put on YouTube would be very helpful. Tricia Nay said that they will be engaging a Johns Hopkins intern to look at the MOLST educational tools and to see what is working with patients. Ted Meyerson said he would prepare an outline of a presentation to propose to the Council. Tricia Nay said she would send Ted Meyerson some educational tools that are being used for MOLST, which tools include discussions of the Health Care Decisions Act and having conversations with patients regarding end-of-life care issues. Alice Hedt noted that there are some basic documents that exist regarding consumer information about these issues.

Delegate Morhaim brought up the issue of the advance directive registry that has never been funded in the State budget. He is asking the Department of Health and Mental Hygiene's (DHMH) Secretary Sharfstein to fund it. The Chesapeake Regional Information System for Our Patients (CRISP) is conducting an electronic records registry project. Delegate Morhaim has heard from the public that health care providers do not have their advance directives.

Tim Keay wondered if consideration had been given to the costs to the public of providing treatments the patient did not want in an advance directive that is unavailable to the health care provider as opposed to the cost of funding an advance directive registry. Senator Manno stated that the underlying legislation authorized DHMH to assess a fee to cover the costs of the advance directive registry. It would not require an additional line item or appropriation for DHMH to fund the registry. He noted the bigger question is whether you have it as a hologram on someone's driver's license or a unique swipeable card that folks could carry with them. Ted Meyerson suggested that the Council support the funding of the registry and Senator Manno agreed.

Tricia Nay said CRISP is working on adding a tab for advance directives and MOLST in the electronic medical records database that can be accessed by health care providers. Senator Manno said other states have implemented a registry at minimal cost and Maryland should not be deterred from doing the same thing simply because the federal government has not yet acted. Tom Smith said that it is a great idea to have an advance directive registry and that advance directives are helpful, but noted that is important to know what is in the advance directive, not just that an advance directive exists. He said it would be most helpful to have a record that notes in one page what the advance directive says. He has seen an instance where someone saw the mere presence of an advance directive noted on the chart as a reason not to provide a life-sustaining treatment to someone who had a curable condition. Thus, the registry needs to be specific regarding the contents of the advance directive and the contents must be able to be pulled up to see what the advance directive says.

Tricia Nay stated she has seen an advance directive as long as 200 pages. Tom Smith asked how often the advance directive registry is accessed in states that have it. Tricia Nay responded that it was not often and far under projections for how much it would be used. She said that when it was tied into a medical record it was accessed more frequently, which makes sense because the doctor is looking in the medical record anyway. She noted that Maryland is close to having something in place through the efforts of CRISP. She said she could update the Council at the next meeting.

Paul Ballard provided an update on the MOLST form and said that DHMH's regulations were repropounded in the Maryland Register and that comments have been received. Paul Ballard shared a note from Council member Gail Mansell that stated that her hospital had already implemented the MOLST form and replaced their internal DNR order with the MOLST form. She stated that implementing the form in the hospital has been well worth it. Tricia Nay noted that over 90% of the nursing homes in the State have implemented the MOLST form voluntarily and that one-third to one-half of acute hospitals have implemented it. There are hospices, large assisted living facilities, and dialysis centers that are choosing to use the MOLST form before it is required. Adult medical day care facilities are also using the MOLST form even though they

will not be required to do so. She also stated that she and Paul Ballard have trained approximately 1450 trainers in 27 all-day train-the-trainer sessions, and that they in turn have trained an estimated 230,000 people.

Paul Ballard discussed the House Bill 1090 workgroup studying palliative care legislation. The workgroup thus far has agreed to the definition of palliative care and the discussions have been productive. He said that the scope of the bill will probably end up being limited to palliative care programs in hospitals.

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