

State Advisory Council on Quality Care at the End of Life Minutes from September 30, 2005 Meeting

Meeting time and place: September 30, 2005, 10:00 a.m., in the Department of Aging's Conference Room, 301 West Preston Street, 10th floor.

Council members present: Dr. Cynda Rushton, Chair; Secretary of Aging Jean Roesser; Ms. Ruth Eger; Dr. Richard Fornadel; Dr. Timothy Keay; Ms. Wendy Kronmiller (Secretary of Health and Mental Hygiene's designee); Rev. John Daniel Mindling; Mr. Ted Myerson; Mr. Jack Schwartz (Attorney General's designee); Ms. Catherine Stavely.

Others present: Mr. Jim DeBoy; Ms. Robyn Elliott; Dr. Lynn Hallarman; Ms. Theresa Jeter-Cutting; Mr. Michael Lachance; Ms. Mary O'Byrne; Mr. William Vaughan.

Dr. Cynda Rushton convened the meeting at 10:00 and welcomed the Council members and guests. Secretary Roesser greeted attendees on behalf of the Department of Aging. Mr. Myerson announced that he had just been appointed to the Council by the Governor, and Ms. Kronmiller announced that she would serve as the Secretary of Health and Mental Hygiene's designee on the Council.

Dr. Rushton invited participants to share any updates or other items of interest. Mr. Myerson noted that the forthcoming White House Conference on Aging would have, as part of its suggested agenda, the topic of advance directive registries. Mr. Schwartz noted that, on October 1, the Patient's Plan of Care form would begin to be offered to new nursing home residents. He also brought to the group's attention two recent publications of interest: *And a Time to Die*, by Sharon Kaufman, a medical anthropologist, concerning the culture surrounding end-of-life decisions in hospitals; and *Taking Care: Ethical Caregiving in Our Aging Society*, by the President's Council on Bioethics. Dr. Rushton reported on progress of the Pediatric Palliative Care Coalition, including issuance of the report from the 2004 Summit, and informed the group of a forthcoming public television series on pediatric end-of-life issues. Also on the subject of pediatric end-of-life care, Ms. Eger announced that Joseph Richey Hospice planned to break ground for its pediatric facility, Dr. Bob's Place, in April 2006; the facility is expected to open in the summer of 2007. Dr. Hallerman shared her recent development of a computerized "patient's plan of care" form integrated into the VA's electronic medical records system. She also directed attention to Joan Didion's powerful article in the *New York Times Magazine* concerning the death of her husband. Dr. Keay reported on the start of a project by the American Bar Association's Commission on Law and Aging to develop a guide to aid health care proxies better understand their role.

The Council then turned to the topic of advance directive registries, and in particular a draft report, previously circulated by Mr. Schwartz, on the issues presented by possible

creation of a statewide advance directive registry. Although the view was expressed that a registry would potentially benefit users, especially if it were easy to use, the Council consensus was that a registry raised serious concerns. A registry, one member observed, would not likely be used by precisely those vulnerable populations who, by dint of linguistic, cultural, and economic isolation, were most in need of an effective means of honoring their wishes. A registry would best serve those who need it least. Two other members expressed the concern that a registry would reinforce a mistaken emphasis on pieces of paper, rather than on the entire process of care. Others raised concerns about privacy issues and the authenticity of registered documents, especially if a person had done a later advance directive that was not in the registry. It was observed that advance directives would likely be more readily available if integrated into medical records, though a member cautioned that special efforts would be needed to raise consciousness about the need to include advance directives in electronic medical records systems.

Council action: *The Council unanimously endorsed the position, contained in the draft report, that the Maryland General Assembly should not move forward with creation of a statewide advance directive registry at this time, but should instead await the report of the Task Force to Study Electronic Health Records.* Mr. Schwartz indicated that, prior to the Council's next meeting, he would circulate a final draft of the report.

The next agenda item was discussion of Mr. Schwartz's "trial balloon" to revise the statutory advance directive forms. Mr. Schwartz had previously distributed, and posted for public comment, a discussion draft. Council members' comments were generally supportive of the effort to simplify the forms. There was debate over the value of using the familiar term "living will." While some comments emphasized the value of prior patient decision making and some uneasiness was expressed over how, in practice, the nonbinding guidance invited by the draft form would work out, others accepted that public policy should be consistent with the evidence that traditional living wills are problematic. Moreover, it was observed that the draft form better served those whose cultures had an understanding of autonomy less focused on the individual as isolated decision maker and more on the individual's desire that decisions be embedded in family considerations. The discussion then turned to the organ donation form that was included in Mr. Schwartz's draft. Comments included the point that a prior patient decision relieved the family of what for many is an emotional decision, that some might become suspicious if the organ donation form were too closely linked to the advance directive itself, and that the form should address the possibility of donating one's body to the Anatomy Board. **Council action:** *The Council, by consensus rather than formal vote, requested that the Attorney General's Office continue work on modifying the statutory forms, in light of the Council's discussion and other comments about the current draft.* Mr. Schwartz indicated that he would soon revise the draft and post a new one for comment.

The last item was a follow-up to discussion at the June 17 meeting regarding an endoscopy center's informed consent document, which included a clause informing patients that their advance directives would not be honored at the center. Mr. Schwartz presented a revised draft letter to Delegate Bobo, which took into account Council members' objection to a position that might encourage ambulatory surgical centers to ignore all advance directives. The revised draft included the following proposed language for the informed consent document: "I understand that, in the event of a life-threatening emergency, this center will normally provide medically appropriate emergency care until I can be transferred to an acute care hospital. If I have an advance directive that would affect care in an emergency, I will bring it to the center's attention and discuss how it should apply." **Council action:** *The Council unanimously endorsed the proposed letter to Delegate Bobo.*

The Council set its next meeting for December 2, 2005, at 10:00 at the Department of Aging.

No further items of business having been presented, Dr. Rushton adjourned the meeting at 12:00.