

State Advisory Council on Quality Care at the End of Life Minutes from June 17, 2005 Meeting

Meeting time and place: June 17, 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; Ms. Muriel Foos; Ms. Marguerite Gilner; Ms. Karen Kauffman; Dr. Timothy Keay; Dr. Steven Levenson; Rev. John Daniel Mindling; Mr. Jack Schwartz (Attorney General's designee).

Others present: Mr. Jim DeBoy; Dr. Lynn Hallarman; Ms. Theresa Jeter-Cutting; Mr. Stephen Johnson; Mr. Ted Myerson; Ms. Elizabeth November; Ms. Leslie Piet; Mr. Paul Seifert; Dr. Gary Wilks.

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, and thanked the Council for its work. She noted that Deputy Secretary Carol Baker plans to attend Council meetings on a regular basis.

Council members and visitors discussed the impact of the Schiavo case on Council objectives, including the following topics:

What members have been doing in the aftermath of the Schiavo case:

Mr. Schwartz and Rev. Mindling reported that the number of requests for advance directive forms and speaking engagements has significantly increased. Mr. Schwartz reported heavy use of the Attorney General's web pages on advance directives: sample advance directive forms have been downloaded approx 80,000 times over the last few months, a 2000% increase from a comparable earlier period. Rev. Mindling noted that the death of the Pope, occurring shortly after the death of Mrs. Schiavo, also generated interest in end-of-life planning. Dr. Keay reported increased interest in advance directives among the students and faculty at University of Maryland. He has been advising them to complete Durable Powers of Attorney for Health Care instead of just completing Living Wills.

What members can do to capitalize on the heightened public interest in advance care planning and to encourage people to focus on patient-centered goals:

Dr. Rushton noted the need to draw people's attention away from an undue focus on treatment-specific written advance directives and refocus their attention on discussions about goals for care. Several attendees gave suggestions on how this could be accomplished. Ms. Foos suggested encouraging hospitals to provide physician education; recommendations could be conveyed to hospitals through letters sent from the Office of the Attorney General. Mr. Schwartz noted his distribution of the Council's document presenting an ethical framework for advance care planning, which emphasizes the process of planning. Ms. Piet mentioned the popularity and effectiveness of "advance directive

parties,” small gatherings of families and friends at which participants discuss their health care wishes and create written advance directives. The Council and guests discussed the need to enlist community partners (e.g., churches, local health departments, law offices) to educate people on advance care planning.

Mr. Schwartz provided an update on legislation from the 2005 legislative session:

A bill was enacted requiring the addition of HIPAA language to the optional health care agent advance directive form in the Health Care Decisions Act. The law is effective October 1, 2005. Mr. Schwartz has incorporated the language into the materials available through the Attorney General’s website and telephone “hotline.”

House Bill 1004, proposing the creation of registry for Durable Powers of Attorney for Health Care, was not enacted. Although the Council was not supportive of this bill, it planned to engage in a summer study of advance directive registries. Mr. Schwartz noted this study is timely in light of the Governor’s interest in an advance directive registry. Mr. Schwartz and Ms. November updated the Council on the progress his office is making in researching the creation of a statewide advance directive registry and drafting a report on this topic. A draft of the report’s Executive Summary was given to attendees, and the outline for the report was presented. Attendees commented on the issues that should be discussed in the report. Once complete, a draft of the report will be distributed to Council members for review and comment.

Mr. Schwartz asked Council members to consider the need to revise the statutory advance directive forms (Maryland Code, Health -- General 5-603), which are the forms on the Attorney General’s webpage (<http://www.oag.state.md.us/Healthpol/advance.pdf>). Mr. Schwartz distributed a discussion draft revision of the forms, and requested that this be an item at the next meeting.

Dr. Rushton reported on the recent the creation of Pediatric Palliative Care Coalition of Maryland. She distributed a document with eight recommendations by the Coalition. The Council’s attention was drawn to the recommendation for the development of innovative models of care of pediatric patients. Along these lines, Ms. Eger reported on plans to construct a pediatric hospice facility and Ms. Piet reported an initiative at Johns Hopkins to insert palliative care guidelines into all care management programs. The Council’s attention also was drawn to the recommendation for the development of pediatric-focused policies and practices. This recommendation cites the Council as the “. . . ideal mechanism to review, evaluate, and recommend policies to the Maryland General Assembly.”

Mr. Schwartz presented a draft letter to Delegate Bobo 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. The letter recommended revising the clause to state that the “. . . center will provide medically appropriate emergency care

until [the patient] can be transferred to an acute care hospital.” Council members objected to endorsing a position that might encourage ambulatory surgical centers to ignore all advance directives. Rather, these centers should take advance directives seriously and work with patients to determine how to proceed in the event of an emergency. Mr. Schwartz will revise the letter and circulate a new draft prior to the next Council meeting.

Mr. Schwartz commented on the status of the Patient’s Plan of Care form. The comment period on the form ended June 13, 2005. Comments suggested relatively minor changes in a few places but did not criticize the document’s elements or design. Mr. Schwartz will review the comments and make appropriate changes to the form, but he did not anticipate the need to republish it for further comment. He anticipates establishing October 1, 2005, as the date on which nursing homes will be required to start offering the form. Other types of facilities are free to decide on their use of the form. Ms. Foos reported she received \$5,000 check from a hospice patient, to be used for efforts related to the form. The Council will consider how this money can best be used. Mr. Schwartz suggested that the funds, especially if augmented from other sources, might be used for evaluating the effectiveness of the form.

The Council set its next meeting for September 30, at 10:00 at the Department of Aging. No further items of business having been presented, Dr. Rushton adjourned the meeting at 12:00.