

**Minutes from April 25th, 2003 Meeting of the
State Advisory Council for Quality Care at the End of Life**

Meeting time and place: April 25, 2003, 10:00 a.m., in the Conference Room of the Department of Aging, 301 West Preston Street, 10th floor.

Council members present: Ms. Lennita Anderson-Selvey; Ms. Ruth Eger; Ms. Sharon Fine; Ms. Muriel Foos; Dr. Richard Fornadel; Hon. Barbara Frush; Ms. Marguerite Gilner; Karen Kauffman; Dr. Timothy Keay; Dr. Steven Levinson; Rev. Daniel Mindling; Ms. Toni Pajardo; Dr. Cynda Rushton; Mr. Jack Schwartz (Attorney General's designee); Ms. Catherine Stavely.

Council members unable to attend: Ms. Carol Benner (Secretary of Health and Mental Hygiene's designee); Ms. Melinda Evans; Hon. Paula Hollinger; Rabbi Mark Loeb; Hon. Jean Roesser.

Others present: Mr. Anand Das; Mr. Michael Lachance; Ms. Lin Layton; Ms. Jacqueline Phillips; Dr. Karen Spencer; Ms. Deborah Tervalá.

Ms. Jacqueline Phillips, Deputy Secretary of Aging, opened the meeting and conveyed Secretary Jean Roesser's regrets that she could not attend due to a prior commitment in Annapolis. Ms. Phillips then welcomed the group and introduced Dr. Cynda Rushton, Chair of the End of Life Council.

Dr. Rushton proceeded to describe the Council's charge, including the making of recommendations to the Office of the Attorney General (OAG) and the Department of Health and Mental Hygiene; advising the General Assembly on legislative matters; and promoting educational efforts with respect to end of life issues.

Mr. Jack Schwartz, Director of Health Policy in the OAG, then described how the Council came into being. He stated that advisory groups of the Governor's office and the Attorney General, respectively, were formed subsequent to the passage of the Health Care Decisions Act in 1993 and functioned for relatively short periods of time. This Council, he explained, differs from those groups in that it has a broad legislative mandate to provide ongoing oversight of issues related to quality care at the end of life.

Delegate Barbara Frush, the principal sponsor of the legislation creating the Council, emphasized the importance of the issue to the citizens of the State. She expressed her personal commitment to pursuing improved care for those with life-limiting conditions and indicated that she would look with great interest to future legislative recommendations from the Council.

Dr. Rushton then noted four issues that stood out after her discussions with Council members: These were: (1) public education and communication to patients and care givers alike; (2) pain in nursing home residents; (3) effective implementation of laws and regulations; and (4) training in palliative care for physicians and nurses. She then introduced Dr. Karen Spencer, Assistant Director of Continuing Education at the Johns Hopkins School of Nursing, to facilitate the rest of the discussion.

Dr. Spencer went around the room calling on Council members to talk about their involvement with end-of-life issues and what their hopes were for the Council. Several themes emerged from the discussion:

- Caring for underrepresented constituencies
- Devising strategies and principles to help implement laws
- Designing appropriate systems of accountability for the delivery of quality care
- Managing pain and deciding when intervention needs to occur
- Removing the bureaucratic burden around advanced directives
- Ensuring that regulations and laws don't get in the way of delivering care to patients
- Addressing patients' fears about dying
- Helping terminal patients access services
- Experimenting with non-pharmacological services for pain management
- Allowing for and accepting the "natural order of things"
- Establishing a supportive platform for physicians to provide palliative care

Dr. Spencer then organized these themes into five issue areas:

1) Education for the Patient, Family, and Public

(This category will address changing attitudes and behaviors in addition to information provision).

Committee Volunteers:

Ms. Marguerite Patricia Gilner, Ms. Toni Pajardo, Ms. Sharon Fine

2) Obstacles to Implementation/ Red Tape Reduction

Committee Volunteers:

Delegate Barbara Frush, Dr. Rick Fornadel, Dr. Tim Keay, Dr. Steve Levenson

3) Review of Existing Legislation

Committee Volunteers:

Delegate Barbara Frush, Ms. Catherine Stavely, Ms. Lennita Anderson-Selvey, Ms. Lin Layton

4) Advanced Care Planning

Committee Volunteers:

Ms. Jacqueline Phillips, Ms. Murt Foos

5) Underserved Populations

Committee Volunteers:

Dr. Cynda Rushton, Rev. Dan Mindling, Ms. Ruth Eger, Ms. Karen Kaufmann

Council members agreed that each committee would meet as needed (and by conference call if more convenient) prior to the next Council meeting. Each committee will provide a report that includes two main components: (1) a review of the issue and (2) a series of proposed action items.

The Council's next meeting time was set for Friday, June 20th from 10:00-12:00 in the Department of Aging Conference Room.