

Palliative Care and Quality of Life Interdisciplinary Advisory Council

June 24, 2014 Meeting Minutes

Members Present:

Jean Anderson, R.N., CEO, Visiting Nurses Service of Newport and Bristol Counties; **Maria Barros, R.N.**, Director of Clinical Services, Nursing Placement, Inc.; **Rev. Marie Carpenter**, Director of Eldercare Ministries, American Baptist Churches of Rhode Island; **Dr. Linda DelVecchio-Gilbert**, Associate Professor, New England Institute of Technology, Nursing Department; **Nancy Roberts, MSN, R.N.**, President and CEO, VNA of Care New England Health System; Chair of the Advisory Council, **Dr. Edward V. Martin, M.D., MPH**, Medical Director, Home and Hospice Care of Rhode Island; **Dr. Angela Taber, M.D.**, Palliative Medicine Physician, Miriam Hospital and Rhode Island Hospital; **Dr. Joan M. Teno**, Professor of Health Systems, Policy and Practice, Brown University School of Public Health.

Members Not Present/ Excused:

Linda M. Dziobek, R.N., Chair, Partnership to reduce Cancer in Rhode Island; (excused)

Staffing the Advisory Council:

Manuela Raposo, Comprehensive Cancer Control Program, Rhode Island Department of Health

Members of the Public Present:

Rele Abiade, Office of Senator Whitehouse; **Jim Willsey**, Roger Williams Medical Center

Present from Rhode Island Department of Health (HEALTH):

C. Kelly Smith, MSW, Comprehensive Cancer Control Program, Rhode Island Department of Health
Minutes:

1. Introductions, Roll Call and Establishment of a Quorum (Chair)

Dr. Martin welcomed and thanked the Council Members and Members of the Public. He then called roll (results above). A quorum of the Council was determined to be present.

2. MOLST (Medical Orders for Life-Sustaining Treatment)

The Council then discussed the MOLST (Medical Orders for Life-Sustaining Treatment) Letter that was sent out for the Council to review. The Advisory Council encourages that MOLST be incorporated into Current Care, and that softer language is used. Letter will be finalized and sent to Dr. Fine.

3. Goals and Objectives for Palliative Care

Key discussion points:

Dr. Martin reminded the Council that January 1st, 2015 is the deadline for healthcare organizations to be in compliance with process for patients to access Palliative Care. A discussion ensued regarding the definition of palliative care and access to palliative care. Healthcentric Advisors has done good work on palliative care; they just qualified 19 nursing homes to do the five protocols around palliative care. The group is in agreement that the focus should not be just end of life, that a culture change is needed in regards to palliative care. The critical piece is the cultural change and education. Two key parts to the issue: Increasing understanding of what makes someone eligible for palliative care and once clear on identification, institution and provider is education and preparation to provide the care. With increased education and awareness we need to find out who are the providers of these services

- Dr. Martin stated that *HEALTH can include questions on access to palliative care on their surveys when surveying nursing homes and hospitals.* The Advisory Council can advise on what constitutes palliative care and report on survey process and what can be done to improve access to palliative care in order to change policy.

- *Resources can be listed on the HEALTH website.* Resources can be obtained from different groups around the state; the Partnership to Reduce Cancer can provide educational resources although they are still in the process of compiling this information. Website should provide information on differences in palliative care services in order to educate people on this topic

- *The IOM report on palliative care should help to shape Rhode Island's practices.* The five questions for the primary care physicians that were outlined in Dr Tenos article should be used as a model to develop five questions for the patient, family member or the decision maker. Everyone agreed this was something to be focused on as an early project

- Having transparency and reporting on data will reassure the public

- Look at concurrent care in other states that allow for Pediatric patients to receive regular pediatric care in addition to palliative care.

First steps:

- Ask that HEALTH via surveying efforts, ask questions about access to palliative care
- Provide advice to surveyors on what is a high quality palliative care program
- A survey will be sent out to CAPSE, HIPNA, ABN and RISNA in order to identify professionals that are credentialed in this area- Dr Teno
- Palliative resources that can be added to the HEALTH website will be identified

4. **Topics for Future Consideration at Meetings:**

Members of the public suggested the following topics for further consideration:

- Resistance of physicians around palliative care-lack of understanding of a need for that extra level
- Patients view palliative care as end of life care, making physicians resistant to referring patients

5. **Future Meetings**

The Advisory Council members will meet every other month, on the last Friday of the month, from 3:30pm to 4:30pm. Next meeting dates will be rotated forward a month in order to accommodate for the holidays: Doodle will be sent out to confirm the meeting schedule.- Manuela Raposo

- September 26th
- November 14th
- January 30th

Adjournment: The meeting was adjourned at 4:32pm. (Minutes reported by Manuela Raposo)