

Palliative Care and Quality of Life Advisory Council

Monday October 30th 2017

Location: American Cancer Society
9850 Nicholas St #200 Omaha Ne 68114

Holly Adams
Marcia Cederdahl
Jennifer Eurek
Dr. Stephen Lazoritz
Dr. Andrew Macfadyen

Linda Rock – by phone
Dr. Todd Sauer
Sabrina Schalley
Stacie Sinclair

Guest:
Sara Morgan

Open Meeting Act Announcement made in accordance with the Nebraska Statue Open Meetings Act a notice of this public meeting and the agenda was posted in the State of Nebraska Public Meeting Calendar, the Women's Health Initiative (Women's Health) website and on the wall by the entrance to the meeting space. A copy of the Open Meeting Act and the agenda is available at each publicized location for this meeting.

Tina Goodwin called the Palliative Care and Quality of Life Advisory Council (Council) to order. There were introductions from Council members/staff that attended the meeting. Tina welcomed the members and explained the purpose of the open meeting act and how public/guest are also invited to meetings. Each member was provided a summary of the *Open Meeting Act*.

Stacie Sinclair explained that all hospice is palliative care but, not all palliative care is hospice (i.e., palliative care is appropriate for anyone regardless of diagnosis, prognosis, age, etc.). Dr. Sauer stated that everyone can do palliative care and palliative care and quality of life go hand in hand. Dr. Sauer mentioned that there needs to be clarification of what palliative care is and what it all means since right now it is so vague.

Dr. Sauer stated that there are two types of palliative care:

- 1) Primary palliative care – teach all doctors to provide management primary palliative care
- 2) Expert palliative care – next level type for palliative care

Andrea Wenke reviewed the *Palliative Care and Quality of Life Act (LB323)*, which was established to ensure the use of palliative care for the quality of life of a patient. The departments shall make information available on the website that includes:

- Referral information
- Education materials for consumers of palliative care
- Consulting
- Conducting a survey

The bill talked about a survey for palliative care providers regarding best practices and recommendations. Andrea explained different educational models that could be included on the website, with guidance from Council members. Andrea reviewed packet of information including the press release “Veterans Home Unveils Palliative Care Suites.” Other information included:

- ❖ CHI Health’s palliative medicine resources
- ❖ Service directory for palliative care
- ❖ Provider directory for palliative care
- ❖ Aging Partners

Stacie Sinclair discussed her work at Center to Advance Palliative Care (CAPC), which is a national non-profit that provides tools, training, and technical assistance to palliative care programs. One of CAPC’s initiatives is the [National Palliative Care Registry](#)TM which tracks operational metrics of palliative care programs across the country. She mentioned that CAPC also recently launched the [Mapping Community Palliative Care](#) project which will ultimately result in an updated national directory of community-based palliative care programs, including what services they provide. Andrea mentioned that DHHS has a directory from the Nebraska Network of Care which includes:

1. Pediatric palliative care
2. Geographical location of providers

Jennifer Eurek stated that she could partner with the Nebraska Hospice Association and DHHS through Licensure to send out a survey which would come from Council members.

Tina introduced a draft of guidelines for the Council and explained that the Council needs to have quorum for each scheduled meeting. The agreed to hold four meetings as there is much to do in this next year. Tina reviewed the section under “Officers” and Dr. Stephen Lazoritz volunteered to be Chair Person and nominated Dr. Todd Sauer to be Vice Chair.

Tina discussed the process of reviewing and writing letters of support of legislative bills. Jennifer Eurek volunteered to head the efforts to discuss and review legislative bills as she monitors legislative bills for the Nebraska Health Care Association.

Marcia Cederdahl went over some of the palliative care definitions with Council members. Some of the definitions of palliative care were taken from:

- Centers for Medicare and Medicaid Services
- National Quality Forum
- National Consensus Project for Quality Palliative Care
- CAPC

In considering the definition of palliative care, Dr. Sauer asked if audience was provider, consumer or both. Dr. Lazoritz mentioned that his organization produced materials written to a 6th grade reading level, and considerations are made for health literacy. Andrea shared that in her

research, it is a good idea to consider different cultures and the diversity of people when developing definitions. Dr. Macfadyen stated that the Council should determine who the audience is first. Jennifer Eurek mentioned that there is no common, recognized definition of palliative care for the health care professionals in the state. Jennifer Eurek stated that Council members need to come up with one idea for both the consumers and the health care professionals. The Council decided to use the [CAPC definition of palliative care](#) in the guidelines. Jennifer Eurek had some handouts with information on palliative care from Nebraska Hospice and Palliative Care Association:

1. 2017 Nebraska End-of-Life Survey Report, Key Findings for Physicians
2. Nebraska End-of-Life Survey Report, July 2017

Holly Adams stated that the survey report information had plenty of information in it, and the way it has been laid out was very helpful. Linda Rock agreed that the surveys were well done.

Tina and Andrea discussed the budget for the Council. Andrea let Council members know that DHHS Communications could help with the website. Andrea talked about travel reimbursement. THE COUNCIL discussed different locations that Council meetings could be held at for free.

1. American Cancer Society, Omaha
2. State Office Building, Lincoln
3. Nebraska Health Care Association (contact Jennifer Eurek)
4. Children's Hospital, Omaha
5. Nebraska Medicine
6. American Cancer Society, Lincoln
7. Visiting Nurses Association (VNA)

Next Steps on the Agenda:

- Dr. Lazoritz and Dr. Sauer would like to talk about the best practices in next the agenda
- Dr. Lazoritz would like to do an educational segment at each meeting. At the next meeting featured presentations will be given by: Stacie Sinclair to discuss her role as Senior Policy Manager at CAPC, and Dr. Sauer, Pediatrician at Palliative Care Associates
- Dr. Lazoritz talked about having a segment on opioid use in an upcoming agenda
- Members will need to discuss how to meet the legislative mandate to complete the "survey of palliative care providers regarding best practices and recommendations."
- Would the Council be interested in endorsing the CAPC survey that is currently in progress?

Members will be sent a Doodle Poll to schedule 2018 Palliative Care Meetings

The Next meeting will be January, 2018

Meeting Adjourned at 3:30

Minutes: Christine Esch