

MEETING MINUTES
Palliative Care Advisory Council
November 5, 2018
1:00 p.m. to 3:00 p.m.
Omaha, NE

Members In Attendance:

Holly Adams
Marcia Cederdahl
Andrew Macfadyen
Todd Sauer
Holly Adams
Stacie Sinclair

Phone:

Linda Rock
Sara Morgan

Staff:

Shirley Pickens-White
Andrea Wenke
Christine Esch

Absent:

Stephen Lazoritz
Sabrina Shalley
Rebecca Martinez

Dr. Sauer called the Palliative Care Council meeting to order at 1:15 p.m. and introductions were made. Dr. Sauer mentioned that the open meeting act was posted which everyone could read.

Open Meeting Act Location Announcement: In accordance with Section 84-1412 of the Nebraska Revised Statutes, a copy of the Nebraska Open Meetings Act is located on the counter near the door.

Approval of Minutes:

Dr. Sauer and the members reviewed the minutes from August 6, 2018 meeting. Holly mentioned the change in the minutes where it was stated that Holly suggested going to the DHHS committee through the Unicameral. Stacie thought that it was an open discussion from the council members in how to reach out to the governor's office or other legislatures in the state about the opioid policy paper. Marcia mentioned about putting the minutes on the Palliative Care website. Dr. Sauer made the first motion to accept the meeting minutes and Holly did second the motion to accept the meeting minutes.

Opioid Policy Paper Follow-up:

Stacie talked about the follow-up on the Opioid Policy Paper with the council members. Stacie mentioned that the Nebraska Research Legislative office prepared a great report about opioid abuse in Nebraska and it is not a big health problem as alcohol and methamphetamines abuse. Stacie stated the Nebraska Palliative Care and Quality of Life Council recommends a balance approach that will address the underlying causes of the opioid crisis while preserving access for patients in need. Stacie feels that the opioid paper is almost complete but, there needs to be more input with positive recommendations on what were for and then fill out one more testimonial. Dr. Sauer wanted to know what Stacie was looking for in one more testimonial. Stacie stated that one of the testimonial is sharing what experiences of caring for people with serious illness. Dr. Sauer and Marcia agreed to submit written testimony for the Appendix. Stacie wanted to know how the

council could get their ideas in front of the legislature. Stacie mentioned to the council about the questions comments, or goals they may have on getting the Opioid Policy Paper done by December 31, 2018. Council members in attendance agreed it was a priority to finalize and disseminate the (Opioid Position Statement) to the legislature prior to the next legislative session (convening in January 8, 2019). No one knew of a formal process for ensuring the paper would reach policymakers; one suggestion was to contact the Health and Human Services Committee.

Palliative Care Best Practices:

Per Marcia, Lou Lukas from the Nebraska Medical Association (NMA) has requested the Council's support for the Nebraska Emergency Treatment Orders (NETO) during the next legislative session. NMA's proposed approach is to work with a Senator to amend "The Rights of the Terminally Ill Act," the goal being to promote a standardized, patient-driven form to ensure that people's care at the end of life is consistent with their wishes. The Nebraska Hospice and Palliative Care Association (NHPCA) supports this or a similar approach.

- Council members in attendance agreed that supporting patients in communicating their wishes is an appropriate activity for this body but had several concerns with the proposed approach:
- Historically, there has been powerful resistance to standardized forms for end-of-life care (and POLST) in NE for various reasons. The Council must therefore do more research and relationship building before taking a position on a potentially controversial issue.

The two action items from the meeting were:

- Full Council to review NETO materials to better understand what is being considered
- Marcia Cederdahl to clarify with Lou Lukas what is being asked of the Council.

Palliative Care Website:

Dr. Sauer mentioned that the council could discuss the website more at the next on February 4, 2019. Andrea discussed some of the features that will be on the palliative care website. Andrea stated that she will send the council members a copy of the link to the website and then they can give their feedback on it. Andrea mentioned that the website should be done by the end of November and then it officially goes live in January of 2019. The palliative care website will be discussed at the next meeting which will be on February 4, 2019.

Policy Barrier "Bucket #1" – continued discussion:

Stacie discussed more about the Policy Barrier "Bucket #1" with the council members. Stacie went over that there is no basic standards for palliative care beyond what is written in the hospice regulations. There are a couple problems with that and they are:

- That there is no shared understanding of what palliative care is.
- Any definitions that is housed underneath the hospice care regulations then people automatically think palliative care is hospice care.

In relating to the definition, members thought it prudent to use the CMS definition as a foundation. The Center to Advance Palliative Care (CAPC) also developed a resource that include sample definitions and standards from other states. Since council members in attendance did not know the process for revising state code and/or regulations, Marcia volunteered to set up a fact-finding discussion with Becky Wisell in the licensure unit at DHHS.

Regarding the landscape study, potential starting points included:

- Using Florida's Palliative Care Report methodology (and similar efforts from other states).
- Recruiting research support from a local university (perhaps a student working on her/his thesis, as previously suggested by Steven Lazortz)
- Identifying data needs from DHHS, as well as proxies if desired data isn't available. Shirley Pickens-White confirmed she would be willing to follow up with the appropriate departments once she was given the data.

Stacie stated once they have the clear definition for palliative care then it can be determined:

- Where do we want that definition inserted into the regulations if it is one place or multiple places?
- How do we get that processed moving?

Palliative Care Month Activities-Focus on Public Awareness:

November is National Palliative Care Month. The main activity planned in NE so far is the Governor signing a proclamation on November 19, 2018 at 11:00 a.m. Council members in attendance discussed the following additional activities:

- Social media promotion from DHHS, NHCA, NHPCA, ACS and others using the National Hospice and Palliative Care Organization's (NHPCO) materials. For the purposes of the Council promotion, any social media language should not include "hospice"
- Press release from DHHS that promotes the month, including a line we now have a website. Shirley Pickens-White volunteered to run this by DHHS communications department if the council drafted the content. NHCA and ACS have mentioned willingness to do a simultaneous press release as well.
- Reach out to the Lincoln Journal Star and Omaha World Herald to see if they would will to do a piece. Dr. Macfadyen mentioned that he would reach out to Children's media/Omaha World Herald about a potential story. Holly stated that she would reach out to the Lincoln Journal Star for a potential story. Marcia will provide NHPCO and ACS language to Shirley and Andrea for a social media and press release.

Agenda and planning for next meeting follow-up:

1. Christine revised the May 7, 2018 minutes to strike Holly sentence regarding DHHS and the Unicameral.
2. Andrea will amend intro text to "For Providers" so it reads like narrative, rather than conflicting definition.
3. Andrea will post meeting minutes on the website.
4. The full council to submit additional changes to Andrea in writing, with the understanding that these might not be incorporated until revisions to the DHHS website are completed.
5. Dr. Sauer and Marcia Cederdahl to provide testimony to Stacie by November 30.
6. The full council to review NETO materials to better understand what is being considered.
7. Marcia to clarify with Lou Lukas what is being asked to the council.

The meeting adjourned at 3:00

Next meeting on February 4, 2019 in Lincoln and the place (TBD)

Christine Esch