

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

June 6, 2022

1:00 p.m. to 3:00 p.m.

Zoom

Members in Attendance:

Marcia Cederdahl (via Zoom)
 Todd Sauer (via Zoom)
 Andrew Macfadyen (via Zoom)
 Julie Masters (via Zoom)
 Angela Mortensen (via Zoom)
 Sabrina Schalley (via Zoom)
 Theresa Jizba (via Zoom)

Staff:

Christine Esch (Office Bldg.)
 Shirley Pickens-White (Office Bldg.)

Guests:

Marilee Malcolm (NHPCA)
 Matt Prokop (ACSCAN NE)
 Megan Word (ACSCAN NE)
 Lou Lukas (Director Palliative Medicine at VA and UNMC)
 Leslie Bonelli (Care Transitions Director, Bryan Health)
 Lori Mills (Bryan Health)
 Andy Link (ACS)
 Kelly Mand (Time to Heal Foundation)
 Tamara Robinson (NC2)

In accordance with Section 84-1411 of the [Open Meetings Act](#), advanced publicized notice of the time and place of this meeting was posted on the [Nebraska Public Meeting Calendar](#).

Agenda Topic	Key Points	Action Items (if any)
Call to Order, Introduction, Meeting Minutes	<ul style="list-style-type: none"> • Todd called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 1:00 pm CT and read the NE Open Meetings Act: <ul style="list-style-type: none"> ○ <i>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 [online].</i> • No corrections. Dr. Macfadyen called the motion to approve the meeting minutes from March 7, 2022; Marcia Cederdahl seconded the motion; all in favor. 	<ul style="list-style-type: none"> • N/A
Nebraska Hospice and Palliative Care Association Update <i>(Marilee Malcolm)</i>	<ul style="list-style-type: none"> • By July 4th, the End-of-Life Survey will be distributed to 3,000 Nebraska residents. • NHPCA fall conference for veterans will be in September 2022, pending speaking availability from Dr. Lou Lukas. • Spring 2023 NHPCA conference in the planning stages. 	<ul style="list-style-type: none"> • Marilee Malcolm to return to committee to share End-of-Life survey results when available. • Council Members to notify Marilee if willing/able to speak at

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<p>Council Report to the Governor and Legislature Dissemination <i>(Marcia Cederdahl, Megan Word, Matt Prokop)</i></p>	<ul style="list-style-type: none"> • Matt Prokop shared ideas on ways to get the word out on the report/council. The draft palliative care “Report Media and Social Media” checklist included: <ul style="list-style-type: none"> ○ Summer (June/July/August) <ul style="list-style-type: none"> ▪ Create graphics that can be shared on social media. (quotes/stats from report) ▪ Create and distribute LTES highlighting findings in report with goal of get at least one letter published per month ▪ Consider running banner ads for online newspaper websites with clickable link to report or summary of report if funding is available ▪ Identify and develop list of newsletters/monthly communication pieces distributed by supporting organizations who could share information on report ▪ Develop press release on report in connection to National Cancer Survivors Month ○ Fall (September/October/November) <ul style="list-style-type: none"> ▪ Schedule meetings with senators to share findings of report. ▪ Webinar in connection to Palliative Care awareness month in November or December as way to start conversation ▪ Op-ed signed by council member • The ACS Health Equity Council has monthly meetings and would like a committee member to attend the meeting in late June 2022 to discuss health disparities in palliative care. Stacie Sinclair willing to join unless others are interested. • Andy Link introduced himself as a member of the Cancer Support team at ACS where he aims to ensure that healthcare facilities are aware of all the programs that ACS has available for patients. • Megan Word reported that there are many new Nebraska senators and it is “time to move into the policy realm.” Megan will begin setting up meetings with Senators so council members can speak with them about palliative medicine. • Dissemination tracker link 	<p>the NHPCA spring conference</p> <ul style="list-style-type: none"> • Council members to contact Stacie if you would like to speak at the June ACS meeting upon request from Matt Prokop (Topic: Health Disparities in Palliative Care)
<p>Council Workgroup – Website</p>	<ul style="list-style-type: none"> • There were no new updates to the website beyond minor technical fixes and a broken link. Any changes should be emailed to Shirley Pickens-White. 	<ul style="list-style-type: none"> • Council members to periodically review website, submit any

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<i>(Andrew Macfadyen)</i>	<ul style="list-style-type: none"> Ongoing request that all Council members (particularly those who are new) review the website to see if the information is clear, anything should be added or changed. Christine Esch forwarded Stacie a report of the “hits” to the council website. Sabrina Schalley reported that new articles have been posted to the council’s website with plans to continue posting articles monthly. Several council members questioned whether the website was sending updates to subscribers. 	<p>changes to Shirley Pickens-White</p> <ul style="list-style-type: none"> Stacie Sinclair to share report of the number of “hits” to the council’s website Andrew Macfadyen to investigate whether the website is sending update emails to subscribers
Council Workgroup – Public Awareness <i>(Marcia Cederdahl, Julie Masters, Sabrina Schalley)</i>	<ul style="list-style-type: none"> Theresa Jizba and Marcia presented to the Nebraska Physician Assistants Committee on 5/6/2022. Stacie and Marcia presented to Franciscan Health in West Pointe, NE who are very interested in palliative care for rural areas. Nebraska Nursing Boards have declined council presentations. Theresa reported an anticipated increase in nursing education on palliative care based upon New Nursing Essentials (released 4/6/2021) that provide a “blueprint” for nursing schools. These guidelines designate hospice and palliative care as one of four “spheres” of nursing education. Link to New Nursing Essentials: https://www.aacnursing.org/Portals/42/AcademicNursing/pdf/Essentials-2021.pdf 	<ul style="list-style-type: none"> N/A
Council Workgroup – Regulatory <i>(Marcia Cederdahl)</i>	<ul style="list-style-type: none"> Marcia reported a desire to adopt a definition of palliative care as a statute; differing statutorily from hospice. Megan Word can provide information on how this was accomplished in Minnesota. 	<ul style="list-style-type: none"> Marcia is reaching out to senator contacts and NHPCO for advice on how to move forward.
Council Operations <i>(Marcia Cederdahl)</i>	<ul style="list-style-type: none"> Marcia reports that Stacie has spoken to Rachel Hays with the Women’s Health Initiatives Advisory Council regarding development of a mission, vision, strategic plan, legislative committee, membership committee, etc. To learn more, Stacie is planning to attend a Women’s Health Initiative meeting and Rachel Hays may join a future Nebraska Palliative Care and Quality of Life Advisory Council meeting to share ideas. 	<ul style="list-style-type: none"> N/A
Public Comments	<ul style="list-style-type: none"> Dr. Lou Lukas shared information about a 12-subject feasibility trial for unresectable pancreatic cancer patients that she will be starting soon. The trial involves administration of psychedelic medications for relief of distress, plus a counseling program aimed at helping patients with an incurable cancer live their best lives. Dr. Lukas recommended that Council members watch the 	<ul style="list-style-type: none"> N/A

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	<p>following meeting to learn more about this type of therapy: Dosed-2 Psychedelic medicines in terminal cancer care https://www.youtube.com/watch?v=BcHh-d2NWXU</p>	
<p>Planning for the Next Palliative Care Meeting</p>	<ul style="list-style-type: none"> • The next Nebraska Palliative Care and Quality of Life Advisory Council meeting is scheduled for September 5, 2022 from 1:00-3:00pm CT; however, this is Labor Day. The council approved the next meeting to be on September 12, 2022 from 1:00-3:00pm CT. Stacie Sinclair will update the calendar appointment. • Agenda items: <ul style="list-style-type: none"> ○ NHPCA update ○ Council Report dissemination ○ Council workgroup report outs ○ Council Guidelines ○ (TBC) Guest presentation ○ <i>Please submit additional agenda items to Todd Sauer and Stacie Sinclair</i> 	<ul style="list-style-type: none"> • Council members to submit requests for reimbursement to Christine Esch • Council members to submit additional agenda items

Meeting Adjourned at 2:03 pm CT

Meeting Minutes: Theresa Jizba