

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

September 12, 2022

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

In-Person and Zoom

Members in Attendance:

Marcia Cederdahl
Todd Sauer
Andrew Macfadyen
Julie Masters
Sabrina Schalley
Stacie Sinclair
Theresa Jizba (via Zoom)
Brenda Kastens (via Zoom)

Staff:

Shirley Pickens-White

Guests:

Nikea Brady (Nebraska Hospital Association)
Senator Mark Kolterman
Lou Lukas (Director Palliative Medicine at VA and UNMC)
Marilee Malcolm (NHPCA)
Kelly Mand (Time to Heal Foundation)
Megan Word (ACS CAN NE)

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 Sauer called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 1:09 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. Julie Masters called the motion to approve the meeting minutes from June 6, 2022; Andrew Macfadyen seconded the motion; all in favor.	<ul style="list-style-type: none">N/A
Remarks <i>(Senator Mark Kolterman)</i>	<ul style="list-style-type: none">Senator Mark Kolterman, who sponsored the legislation to create the Council, provided opening remarks. He shared about his background in championing for better quality of life for people living with cancer, and his wife’s journey with pancreatic cancer. Through this, he realized that most people do not know what palliative care is or have the coordinated care they need. He appreciates the work that the Council is doing, including our dedication to the comfort of patients and efforts to raise awareness of palliative care.	<ul style="list-style-type: none">N/A

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	<ul style="list-style-type: none"> Moving forward, he is term-limited, so will be unable to carry more bills. However, he continues to have good relationships across the state (e.g., the Nebraska Medical Association, providers, hospital association, and insurance companies), and is willing to support the Council in whatever way he can. 	
Nebraska Hospice and Palliative Care Association Update <i>(Marilee Malcolm)</i>	<ul style="list-style-type: none"> NHPCA’s fall workshop, “Relieving Suffering for Veterans, Patients, Families, and Caregivers” will take place on October 27, 2022 from 9:00am-4:00pm at the Firespring Conference Room. It will be led by Dr. Lou Lukas. Registration information is available at this link, and the cost is \$25 for NHPCA members, \$75 for non-members The annual NHPCA conference will take place on March 21-22, 2023 at Embassy Suites in Lincoln; the call for presentations is open through the end of October – please let Marilee know if you want to present. NHPCA distributed the 6th consecutive End-of-Life Survey to ~3,000 Nebraska residents. By the end of August, they had a 12% return rate; this is a little lower than previous cycles, so they will continue to follow up. There was a discussion about decreasing availability of pediatric hospice due to closures and changes in ownership. While there are gaps, Council members know hospice providers who continue to take pediatric patients; Sabrina Schalley can provide more information to NHPCA. NHPCA recently hosted a certification prep class for CNAs and another workshop for aides. These professionals have been very excited to gain more knowledge about how to better support people living with serious illness. The Proclamation signing for Hospice and Palliative Care Month will take place on November 7 at 11:00am. NHPCA is still waiting on a room number, which is usually sent out by mid-October. 	<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 the NHPCA spring conference
Age-Friendly Health Systems and Palliative Care <i>(Nikea Brady)</i>	<ul style="list-style-type: none"> Nikea Brady, the Age-Friendly Program Manager at the Nebraska Hospital Association presented on the Age-Friendly Health Systems program and how palliative care fits into the priority area, “What Matters.” Her presentation will be posted on the Palliative Care Council website. 	<ul style="list-style-type: none"> Stacie Sinclair to send presentation to Shirley Pickens-White to post on website
End of Life Treatment Orders <i>(Theresa Jizba)</i>	<ul style="list-style-type: none"> Nebraska does not have a unified approach to capturing, storing, and communicating end-of-life/do not resuscitate preferences (see minutes from November 2018 and February 2019; the Council took a neutral stance and offered support for both NETO and POLST). Dr. Lou Lukas has been maintaining the Nebraska Emergency Treatment Orders (NETO) website using her own resources; this is unsustainable, and she is willing to share all the supporting resources. NHPCA is open to the idea of “housing” them. 	<ul style="list-style-type: none"> Nikea Brady to follow up with EMS professionals to learn about implementation Stacie Sinclair to confirm that NETO and POLST forms are available on the Council website

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	<ul style="list-style-type: none"> The most important issue is that patients want to know that there is some validity to their form – it is devastating if a form is completed, and then not honored. Most of the implementation challenges come from EMS, which come into the home in complicated and chaotic circumstances. Age-Friendly is working with these professionals, as well as other non-medical providers. Nikea Brady will reach out to her contacts to learn more about current practice. 	<ul style="list-style-type: none"> Council to continue this discussion at the next meeting
Serious Illness Definition and Coalition Building <i>(Marcia Cederdahl, Stacie Sinclair)</i>	<ul style="list-style-type: none"> The Council proposed a few additional edits to the draft palliative care definition. ??? called the motion to approve the revised definition; ??? seconded the motion; all in favor. The Council-approved definition is as follows: <i>Palliative care. "Palliative care" means specialized medical care for people living with a serious illness that carries a high risk of mortality or negatively impacts quality of life. This type of care addresses the pain, symptoms, and stress of a serious illness. Palliative care is a team-based approach to care, providing essential support at any age and stage of a serious illness, and can be provided with curative treatment. The goal of palliative care is to improve quality of life for both the patient and the patient's family or care partner.</i> The next step is to confirm the definition with NHPCA, and then socialize it with other interested organizations across the state. 	<ul style="list-style-type: none"> Stacie Sinclair, Marcia Cederdahl to work with NHPCA to finalize draft definition
Council Workgroup – Public Awareness <i>(Marcia Cederdahl, Julie Masters, Sabrina Schalley)</i>	<ul style="list-style-type: none"> Ran out of time for this discussion, but the Public Awareness workgroup will continue its activities (including working through the inventory of options provided by ACS CAN) as Hospice and Palliative Care Month approaches. Since the May meeting, Stacie Sinclair presented on palliative care to the ACS CAN Health Equity Council; and Council members submitted abstracts to the National Association of Social Workers, Nebraska Chapter; and the American Academy of Nursing. 	<ul style="list-style-type: none"> N/A
Council Workgroup – Website <i>(Andrew Macfadyen)</i>	<ul style="list-style-type: none"> Andrew reported that the number of visits to the website continues to grow, with a noticeable spike in 2022. Julie asked if there was a way to identify which resources visitors looked at the most; this would enable us to target what the needs are, and where we could provide more information. There were no new updates. 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. Any changes should be emailed to Shirley Pickens-White. 	<ul style="list-style-type: none"> Council members to periodically review website, submit any changes to Shirley Pickens-White Andrew Macfadyen to investigate whether the website is sending update emails to subscribers; also see if there is a way to identify

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		which resources are most popular
Mission, Vision, Strategic Planning <i>(Marcia Cederdahl)</i>	<ul style="list-style-type: none"> N/A – pushed to next meeting 	<ul style="list-style-type: none"> N/A
Calendar for 2023 <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> Proposed dates: <ul style="list-style-type: none"> December 5, 2022 March 13, 2023 June 5, 2023 September 11, 2023 December 4, 2023 	<ul style="list-style-type: none"> Stacie Sinclair to send a follow-up email to confirm
Public Comments	<ul style="list-style-type: none"> N/A 	<ul style="list-style-type: none"> N/A
Planning for the Next Palliative Care Meeting	<ul style="list-style-type: none"> The next Nebraska Palliative Care and Quality of Life Advisory Council meeting was not determined. Stacie will send out a follow-up email to schedule. Agenda items: <ul style="list-style-type: none"> NHPCA update Palliative care definition Council workgroup report outs Council Mission, Vision, Strategic Planning (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 Shirley Pickens-White Council members to submit additional agenda items

Meeting Adjourned at 3:04pm CT

Meeting Minutes: Stacie Sinclair