

## MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

December 5, 2022

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

In-Person and Zoom

### Members in Attendance:

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

### Staff:

Shirley Pickens-White  
 Leah Snyder

### Guests:

Shelby Hopp (Nebraska Medicine)  
 Mandy Kirkpatrick (Creighton)  
 Marilee Malcom (Nebraska Hospice and Palliative Care Association)  
 Kelly Mand (ATTH)  
 Abby Stella (CHI Palliative Care Social Work)  
 Megan Word (ACS CAN NE)  
 Carly Woythaler-Runestad (Mourning Hope)

*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)   |
|--|---|---|
| <b>Call to Order, Introduction, Meeting Minutes</b>                  | <ul style="list-style-type: none"> <li>• Stacie Sinclair called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 1:08 pm CT and read the NE Open Meetings Act:                             <ul style="list-style-type: none"> <li>○ <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></li> </ul> </li> <li>• No corrections. Julie Masters called the motion to approve the meeting minutes from September 12, 2022; Marcia Cederdahl seconded the motion; all in favor.</li> </ul> | <ul style="list-style-type: none"> <li>• <b>Carly Woythaler-Runestad offered that Mourning Hope</b> could host future Council meetings that are based in Lincoln</li> </ul> |
| <b>Guest Presentation – Mourning Hope (Carly Woythaler-Runestad)</b> | <ul style="list-style-type: none"> <li>• Carly Woythaler-Runestad, MHA, Executive Director delivered a presentation on <a href="#">Mourning Hope Grief Center</a>. Mourning Hope is a grief support network for children, adults, and families before and after a death loss. Programs and services include (but are not limited to) groups, camps, counseling services, and special events.</li> <li>• Palliative care teams can easily make referrals by visiting <a href="#">this link</a> or emailing <a href="mailto:hope@mourninghope.org">hope@mourninghope.org</a>.</li> </ul>  | <ul style="list-style-type: none"> <li>• <b>Council members</b> to contact <a href="#">Carly Woythaler-Runestad</a> if they are willing to conduct trainings</li> </ul>     |

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|  | <ul style="list-style-type: none"> <li>Council members are invited to volunteer, which can include leading groups (Marcia Cederdahl has done this) and delivering trainings. Sabrina Schalley and other Council members expressed gratitude for Mourning Hope’s trainings and programs.</li> </ul>   |   |
| <b>Nebraska Hospice and Palliative Care Association Update</b><br><i>(Marilee Malcom)</i>              | <ul style="list-style-type: none"> <li>NHPCA finished data collection for its 5<sup>th</sup> statewide End-of-Life Care survey. Nebraska is unique in its consistency – no other state has regularly conducted a similar survey this many times. Julie Masters is helping with the analysis, and findings should be available in early spring. NHPCA is still seeking a sponsor for printing.</li> <li>Preparations for the annual <a href="#">NHPCA Conference</a> are in full swing. It will take place on March 21-22, 2023 at the Embassy Suites.</li> <li>Diana Lecher from Chadron recently joined the NHPCA Board, which is now fully seated.</li> </ul>  | <ul style="list-style-type: none"> <li><b>Council members</b> to contact Marilee Malcom with any leads on printing sponsors</li> </ul>  |
| <b>Serious Illness Definition and Coalition Building</b><br><i>(Marcia Cederdahl, Stacie Sinclair)</i> | <ul style="list-style-type: none"> <li>Stacie Sinclair and Marcia Cederdahl provided an update on the effort to pass a legislative definition of palliative care. The goal is to create a clear and simple definition that establishes a statewide foundation for what palliative care is – distinct from hospice – clarify that it should be team-based, available across care settings and patient populations, and delivered alongside curative treatment.</li> <li>In partnership with NHPCA and ACS CAN, the Council has been talking to relevant stakeholder organizations across the state (e.g., health care institutions, associations, universities, etc.) to build a base of support (“coalition”); drafting support materials; and reaching out to potential co-sponsors. ACS CAN will host an event on December 8 to mobilize supporters; and the Council/NHPCA/ACS CAN will host an event on December 16 to introduce the effort to the broader coalition.</li> <li>Council members and meeting attendees suggested additional organizations that might be inclined to support the effort, including Legal Aid Nebraska, Elder Access, CHI Health Services, the State Unit on Aging, AAA, and Rural Nebraska Healthcare Network.</li> <li>Once the bill is introduced, the Council may receive questions from the Unicameral or DHHS that require rapid responses. The proposed process will be that questions are conveyed to Stacie and Marcia, who will send to the full Council. <b>The Council then has 24 standard hours (not business hours) to respond</b>; following that, Stacie and Marcia will send responses back.</li> <li>Stacie will create a <a href="#">repository</a> to house all definition effort materials including meeting recordings, leave behinds, FAQs, etc.</li> </ul> | <ul style="list-style-type: none"> <li><b>Stacie Sinclair</b> to follow up with suggested organizations/those who volunteered to reach out</li> <li><b>Stacie Sinclair</b> to create repository for definition materials (link <a href="#">here</a>)</li> </ul> |
| <b>Council Workgroup – Public Awareness</b><br><i>(Marcia Cederdahl,</i>                               | <ul style="list-style-type: none"> <li>The Public Awareness Workgroup continues to meet regularly, and was joined by Matt Prokop (ACS CAN) at a recent meeting, as some of the work complements the palliative care definition effort.</li> </ul>  | <ul style="list-style-type: none"> <li><b>Public Awareness Workgroup</b> to send any desired social media</li> </ul>  |

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| <p><i>Julie Masters, Sabrina Schalley</i></p>   | <ul style="list-style-type: none"> <li>• Plans for 2023 include building on what the Council already has in place: <ul style="list-style-type: none"> <li>○ Adding website content on website, including having guest authors submit blogs every other month (e.g., Mourning Hope on the impact of grief).</li> <li>○ Establish a “Speakers Bureau” comprised of Council members and palliative care leaders in the community who are willing to speak and provide quotes.</li> <li>○ Continue social media push. Matt provided example campaigns. Rather than establishing separate social media channels for the Council, the Public Awareness Workgroup said that it will disseminate messages and provide instructions on how members can use. Shirley Pickens-White said that DHHS could promote things on its social media (e.g., LinkedIn).</li> </ul> </li> <li>• Marcia Cederdahl and Sabrina Schalley will be cycling off the Workgroup once they have completed their Council terms, so more volunteers (<b>not limited to Council members</b>) are needed. The Workgroup currently meets monthly via Zoom.</li> </ul>   | <p>messages to Shirley Pickens-White for DHHS promotion; <b>Council Members</b> to amplify through their own organizational and personal social media channels</p> <ul style="list-style-type: none"> <li>• <b>Council members</b> needed to volunteer for the Public Awareness Workgroup</li> </ul> |
| <p><b>End of Life Treatment Orders (POLST/NETO) and EMTs</b><br/><i>(Stacie Sinclair)</i></p> | <ul style="list-style-type: none"> <li>• Stacie Sinclair shared notes from Nikea Brady regarding how first responders (e.g., police officers, EMS) understand and respond to end of life treatment orders. The takeaway is that there is no consistency across counties or jurisdictions, and any attempt to create standardization would require a multi-pronged effort that includes (but is not limited to): first responder education, agreed-upon forms, database interoperability, quality incentives, and patient and family education.</li> <li>• Several Council members reflected on the myriad challenges for this work, including gaps in education and consistency across health care providers (including hospice and palliative care). Theresa Jizba observed that there is no literature that standardizes what EMTs should be asking in the home or in the ED. Marcia Cederdahl noted that Dr. Bob Bleicher presented at the NHPCA conference last spring on the statewide POLST effort, and Marilee Malcom shared that NHPCA has been working on this issue but would welcome partnership.</li> <li>• Council members agreed that this should remain on the Council’s radar. Theresa offered to be the point person, and will follow up on pulling together leads (e.g., Eric Ernst from the Board of Emergency Medical Services, paramedicine contacts), potentially developing a project plan.</li> </ul> | <ul style="list-style-type: none"> <li>• <b>Theresa Jizba</b> to lead EOL Treatment Orders effort</li> </ul>   |
| <p><b>Council Workgroup – Website</b><br/><i>(Andrew Macfadyen)</i></p>                       | <ul style="list-style-type: none"> <li>• Andrew Macfadyen reported that the website seems to be running smoothly; no broken links. Stacie Sinclair observed that the website needs cleaning (there might have been a department-wide website update that moved things around), will follow up.</li> </ul>   | <ul style="list-style-type: none"> <li>• <b>Stacie Sinclair</b> to review website and make proposals for cleaning</li> <li>• <b>Council members</b> to review website and send</li> </ul>  |

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|  |   | any updates to Shirley Pickens-White   |
| <b>Mission, Vision, Strategic Planning</b><br><i>(Stacie Sinclair)</i> | <ul style="list-style-type: none"> <li>Stacie Sinclair expressed the need for a formal strategic planning process that can guide the Council's future work, particularly as a significant number of original Council members will be cycling off in 2023. Council gave permission for Stacie to contact the consultant who led the strategic planning work for the Nebraska Women's Health Initiative Advisory Council.</li> </ul>  | <ul style="list-style-type: none"> <li><b>Stacie Sinclair</b> to contact strategic planning consultant</li> </ul>  |
| <b>Open Discussion and Public Comments</b>                             | <ul style="list-style-type: none"> <li>N/A</li> </ul>   | <ul style="list-style-type: none"> <li><b>N/A</b></li> </ul>   |
| <b>Planning for the Next Palliative Care Meeting</b>                   | <ul style="list-style-type: none"> <li>The next Nebraska Palliative Care and Quality of Life Advisory Council meeting is on March 13, 2023 from 1:00-3:00pm CT. Stacie Sinclair already sent a calendar appointments with a Zoom link; in-person meeting location in Omaha will be confirmed as it gets closer. Subsequent Council meetings are set for: <ul style="list-style-type: none"> <li>June 5, 2023</li> <li>September 11, 2023</li> <li>December 4, 2023</li> </ul> </li> <li>Agenda items: <ul style="list-style-type: none"> <li>NHPCA update</li> <li>Palliative care definition campaign</li> <li>Council workgroup report outs</li> <li>Council Mission, Vision, Strategic Planning</li> <li>(TBC) Guest presentation</li> <li><i>Please submit additional agenda items to Todd Sauer and Stacie Sinclair</i></li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li><b>Council members</b> to submit requests for reimbursement to Shirley Pickens-White</li> <li><b>Council members</b> to submit additional agenda items</li> </ul> |

Meeting Adjourned at 3:01pm CT  
Meeting Minutes: Stacie Sinclair