

Palliative Care Advisory Council

August 2, 2024 | 9:30-10:30am

Meeting Minutes

Members present: Ross Albert, Barbara Cass, Mary Kate Eanniello, Taryn Hamre, ToniAnn Marchone, Kerry Moss, Karen Mulvihill, Joseph Sacco, Natalie Shurtleff, Tracy Wodatch.

Members absent: Jennifer Kapo.

Introduction

- Karen Mulvihill opened the meeting at 9:35am.
- Tracy Wodatch made a motion to approve the June minutes; Joseph Sacco seconded.
 - The minutes passed without discussion.

Public Comment

- Barbara Cass gave an update on MOLST, saying that the law passed removing the requirement for a witness signature, and the council will be discussing the revised Policies & Procedures in their September meeting.
 - Joseph Sacco commented, saying that the requirement to have the original green form seems burdensome, and an eMOLST would be a great solution. Barbara mentioned that the MOLST advisory council is recommending a digital-first approach.
 - Karen asked about changes in the mandatory training; Barbara mentioned that this cannot be removed as it is in the statute, but they will work to provide better access to the training.
 - Mary Kate Eanniello commented that she is a fan of the eMOLST system, and that she works with Barbara Jacobs to do the Hartford Healthcare training via Zoom. They find that holding the training is useful for providers because it starts a conversation about end-of-life decisions. She asked how DPH is keeping track of providers who have had MOLST training, and asked if there is a way for a hospital system to use DPH's registry of trained providers.
 - Barbara responded that currently, Barbara Jacobs sends the list of names of certified providers to DPH Communications to keep track of the data. The group/DPH has looked into a MOLST registry as a future option, but this would require resources.
 - Kerry Moss spoke about the difficulty of witnessing documents for pediatric patients at Connecticut Children's.

Committee Updates

Pediatric Palliative Care Committee Update

- Taryn shared that the Pediatric Palliative Care Coalition website has been updated and is live.

- <https://www.ppcc-pa.org/state-coalitions/connecticut>
- Kerry reported that the coalition is very active, and it is great to see this group get off the ground.
 - They are advocating for nurse pronouncement throughout the state and bereavement.
- Tracy brought up that the legislature is putting together the pediatric hospice working group in the coming weeks – they are hoping to come up with a smaller group to lead, since the legislation includes a seat for every hospice provider in the state.
- Taryn commented in the chat: The Coalition also reached out to hospital based and outpatient organizations to encourage participation in the NHPCA Pediatric Palliative and Hospice Care Needs Assessment Survey with the goal to better understand organizations and providers caring for patients with serious illness in the US. Hopefully it will also help to create resources and support advocacy based on what was shared in the messaging provided.

Infusion Services Committee Update

- Karen, Billy Nolan, and Mary Kate met regarding infusion services – access to community PCA pumps is still an issue.
- Karen reported on Billy’s conversation with Option Care, to learn about the barriers to getting at-home infusion services. The answer included an increase of diversion and misuse, and increased regulation on monitoring and regulation of controlled substances. Option Care reported that the risks were no longer worth the financial gain.
 - Tracy commented that it likely has to do with cost.
 - The group was frustrated at the unwillingness to proceed with at-home infusion services, especially since it prioritizes finances versus the right thing to do for patient care.
- Other thoughts on at-home infusions were shared:
 - At home IV fluids can let the caregivers go to work, and keep people out of the emergency department, because it manages their symptoms.
 - Home infusion services would be instrumental in allowing children to die at home with their families, especially since pediatric facilities do home 24-hour infusions of chemotherapy with children.

Recommendations for Chaplain Appointment

- The group has an open chaplain seat that they would like to fill, Karen asked the group if they had any recommendations. Ideally, they would like to spread out the representation across the state.
- Tracy offered to reach out to Day Kimball Hospital to see if their Chaplain would be interested.
- Karen Mulvihill offered to reach out to Mark Marshall at Visiting Nurse and Hospice of Litchfield County for a recommendation.
- Joseph Sacco recommended that the group reach out to Lori McKnight, as she is connected to other chaplains and spiritual leaders in the state.

Closing

- Natalie Shurtleff flagged that as she settles into her new position, she may have less capacity to serve on the Council.

- Joseph motioned to adjourn; the meeting adjourned at 10:22am.