

Palliative Care Advisory Council

March 1, 2024 | 10:00-11:00

Meeting Minutes

Members present: Barbara Cass, ToniAnn Marchione, Tracy Wodach, Taryn J Hamre, Kerry Moss, Karen Mulvihill

Members absent: Jennifer Kapo

Note: legislative appointments to the council are still being finalized, current members only include those reappointed by the Commissioner of Public Health.

Introduction

- The meeting commenced at 10:04am
- Karen Mulvihill introduced Dr. Marshall, the visiting nurse and Hospice services of Litchfield County, to the council

Remarks from DPH

- Barbara commented that the DPH Commissioner's appointment letters have been completed, and DPH government relations is working with the legislative body to confirm the rest of the council appointments
- Barbara explained that the palliative care advisory council has important work to do, especially as palliative care and hospice are receiving attention in the legislature

General Discussion

Legislative Updates: SB 176

- Karen updated the group on SB 176, which addresses pediatric palliative care in the state
 - There are very few hospice agencies that take pediatric patients
 - There was a public hearing on the bill happened on Mon. Feb 26, a number of palliative care and hospice advocates and providers testified, including members of the council
- Tracy Wodach and ToniAnn shared information that several members who testified were asked by the legislature to submit information on what service to pediatrics looks like, and what would the quality standards be
 - The council has an opportunity to define the framework for pediatric hospice
 - Sen Anwar seems specifically focused on making this bill happen
 - Tracy added that they are hoping to make edits to the bill to enable subject matter experts to shape the policy, using DPH as technical oversight and support
- The group supported the idea of a pediatric-specialty subgroup of the council to help draft the framework for a pediatric palliative care program to better identify the next steps for legislators
- Barbara Cass added that since the group has already identified the problem (access to pediatric palliative care), this council should look at ways to take action now, even starting at the local level, so everyone can contribute to the solution
- Toolkit for pediatric palliative care delivery, could be use to get information from:
<https://www.capc.org/toolkits/designing-a-pediatric-palliative-care-program/>

- On behalf of the council, Karen would like to submit testimony in support of this all of the appointed members were supportive of submitting written testimony

Home Hospice Hospital

- Karen brought up the pilot program resulting from a 2023 act for providing a hospital level of hospice services at home, focused around IV pain medication
- DPH did not see any precedent in this model
 - Karen noted that the problem lies in the availability of infusion companies to help supply IV pain medication, as there are no barriers to the ability to provide these services at home
 - DPH determined (last year) that the necessary statutory and regulatory framework as well as CMS precedent is not in place to support the development of a hospital hospice at home program
- Karen brought up that the council was asked by DPH to address the barriers of providing this level of care at home
 - This is another area where Karen is interested in forming a subgroup to work on this issue
- Barbara asked the group what has happened in the industry that has caused an access issue for infusion services
 - The group answered that the issue lies with reimbursement, and spoke about closure of many infusion therapy companies
 - Kerry Moss shared that she has not been able to give IV meds to kids at home for five years, when the reimbursement changed
- The group discussed about the difficulty of accessing CAD pumps
- Karen is going to put together a small work group to identify and assess the barriers to infusion
 - Ross and Mary Kate will definitely be involved

Planning for the future of the committee

- The council's plan for 2024 is to look at access issues to hospice and palliative care
 - With a special focus on pediatrics, and infusion services
- Karen would like to set up two workgroups: infusion and pediatric
- Going forward, the group will meet at 9:30 on the first Friday of each month

Public Comment

- Mark Marshall expressed that there are resources in the community that the council needs to support and harness – formulating a single agency just to take care of children does not make sense, it is important to expand programs to children from existing palliative care locations
- Mary Kate will distribute a flyer for a symposium on palliative care
- Mary Kate let the group know that she serves on the board of the Connecticut Nurses Association, so if the group has information or concerns that they would like relayed back to the association, she is the point of contact

Annual report

- Karen will add the goals for 2024 to the council's annual report, and submit to Barbara Cass

Closing

- The next meeting is scheduled for Friday, April 5, from 9:30-10:30am

Meeting recording: <https://youtu.be/YqNrx5XxLmk>