

#### 4160 PATTERSON AVENUE – BALTIMORE, MARYLAND 21215 TELEPHONE: 410-764-3460 FAX: 410-358-1236

## Palliative Care Services Workgroup Meeting January 9, 2023 Meeting Summary

#### ATTENDANCE:

Workgroup Members: Dr. Deneen Bowlin, CareFirst Cindy Carter, AARP Erin Davis, Maryland Hospital Association (MHA) Dr. Marian Grant, Palliative Care Nurse Practitioner and Consultant Amanda DiStefano, Maryland Department of Aging Peggy Funk, Hospice & Palliative Care Network of Maryland Dr. Christopher Kearney, State Advisory Council on End of Life Care Cindy Massuda, CMS Joanna Ruth, Maryland Medicaid

#### **MHCC Staff:**

Ben Steffen Linda Cole Tracey DeShields Dr. Stacy Howes Zoram Kaul Cathy Weiss

#### **Interested Parties/Public:**

Dr. Rachel Adams, MedStar Health Tara Coles Leah Couture, MedStar Health Tiffany Daniel, AARP Dr. Ethan Goldstein, MedStar Health Ted Meyerson, Nursing home/ General Interest Maria Moen Dr. Dan Morhaim, Retired Physician and State Delegate Rebecca Swain-Eng, SEA Healthcare Mary Alfonso-Torres, Seasons Hospice Kelly Voltran, CMS

#### WELCOME AND UPDATES:

Linda Cole welcomed the participants to the third meeting of the Palliative Care Services Workgroup. She asked if there were any comments or corrections to the November 14<sup>th</sup> meeting summary. She noted that this is posted on our website in case anyone has comments.

Ms. Cole reported that the bid board contract for conducting the statewide palliative care survey was posted and responses were received on December 23<sup>rd</sup>. After reviewing the proposals, staff awarded the contract to SEA Healthcare. Rebecca Swain-Eng, CEO of SEA Healthcare was introduced to the workgroup. Results from this survey will be shared with the workgroup at future meetings.

# CONSUMER PERSPECTIVES ON PALLIATIVE CARE:

Ms. Cole said that Cindy Carter, representing AARP, had stated in previous meetings that our survey of healthcare facilities does not take into account the perspective of patients and their caregivers. Ms. Cole introduced Cindy Carter and Tiffany Daniel to share their perspectives.

Ms. Carter explained that her assignment for this presentation was to address four questions:

- 1. How were you referred to palliative care/
- 2. What worked well for you?
- 3. What obstacles did you encounter?
- 4. What recommendations can you make to the workgroup?

Ms. Carter stated that she has run the Cancer Support Foundation for 18 years, is a four-time caregiver, and is a cancer survivor. Her experience is that patients are offered hospice or no care; palliative care is not mentioned. In her experience, most patients are treated in the hospital, but they have little or no follow up when they go home. Patients who do not have an able-bodied caregiver at home do not get needed services. What is needed is help with taking care of patients' needs at home.

Dr. Marian Grant noted that she agreed with what Ms. Carter reported. However, she noted that the gaps in services are not just for cancer care, but for all serious illnesses. She also noted that the need for supportive services in the home (e.g., help with activities of daily living) is not palliative care, which is medical care. The lack of funding and access to non-medical support services in the community is a general failure of the health care system, but not the focus of this workgroup.

Dr. Chris Kearney said that palliative care has a role in the hospital, especially when a patient is admitted for uncontrolled symptoms. He agreed that more needs to be done on social determinants of health.

Tiffany Daniel explained her family's experience as both of her grandmothers became caregivers for her grandfathers. Her niece also experienced a cancer diagnosis. Her experience was with the Veterans Administration. Her family was not referred to palliative care. They delayed use of hospice care in the home. Family members rotated providing needed care at home. She said that family members need training to provide such care.

Dr. Dan Morhaim asked about Ms. Daniel's reference to "hospice care in the last days." He stated that hospice should be provided for months.

# DISCUSSION OF STRATEGIES FOR COLLABORATION FOR IMPROVING AND EXPANDING PALLIATIVE CARE SERVICES:

Ben Steffen noted that there seems to be no agreement on where palliative care fits. Is it end of life care or curative care? This is important for payers.

Dr. Grant agreed and pointed out that in areas such as cardiology there is not the same confusion as with cancer care. Palliative care can be offered early in any serious illness until the end of the illness. At the end, care can shift to hospice.

Peggy Funk agreed with Dr. Grant and said that hospice is a Medicare benefit that is offered when a physician indicates that, if the illness follows the average trajectory, the patient has six months or less to live. Many patients do not die within six months, and the benefit can be extended. Palliative care is offered earlier to help manage symptoms and improve the quality of life. Hospice care is part of palliative care; however, hospice care is not curative.

Dr. Rachel Adams said that there is lack of education about palliative care. Also, there need to be incentives to refer to palliative care. Guidelines recommend that for cancer patients they should be referred to palliative care within eight weeks; however, these are only guidelines. She noted that MedStar has nine palliative care programs.

Dr. Grant mentioned that the Hartford Foundation is working on messaging for providers and patients on palliative care. The research indicates that messages should not differentiate palliative care from hospice. References to hospice often scare patients away from using palliative care services.

Dr. Grant also mentioned Clinical Guidelines on referral to palliative care. She stated that some hospitals have triggers in their electronic health records, but these have mixed results. Most hospitals have inpatient palliative care only. At the University of Maryland, there are inpatient palliative care programs, but nothing post discharge.

Dr. Adams said that MedStar has a very successful palliative care program embedded in its inpatient program. MedStar also has community-based programs. Through the PATCH program, telehealth based palliative care is offered. She noted that there are also fellowship programs for palliative care at both MedStar and the University of Maryland.

Erin Davis stated that palliative care is needed across all service lines in hospitals and across all settings. Many providers are not comfortable with speaking about palliative care and patients are often lost in transitions of care.

Ms. Funk pointed out that hospitals do a good job of providing palliative care because recent legislation required all Maryland hospitals with 50 beds or more to provide a palliative care program. The need, and the focus of this workgroup, is on palliative care within the community.

DISCUSSION OF STRATEGIES FOR EXPANDING FINANCIAL SUPPORT FOR PALLIATIVE CARE: Ms. Funk mentioned that Hospice of Washington County has a freestanding palliative care community program. However, this service is expensive and is provided at a financial loss.

Dr. Grant said that other states, such as California and Hawaii, have made palliative care a required benefit under their state Medicaid program. Such an effort encourages the development of palliative care programs across the state. She asked what can be done under the Health Care Services Cost Review Commission (HSCRC) Total Cost of Care waiver.

Dr. Kearney pointed out that advocates need to convince hospital administrators that palliative care is effective in reducing average length of stay, hospital readmissions, use of ICU days. Hospitals are losing money in funding these programs. They would like to share costs under the Total Cost of Care.

Dr. Adams said that MedStar is supporting the palliative care programs. However, many hospital systems are losing staff and cutting costs.

Ms. Davis said that there are opportunities to work under the Total Cost of Care model. She would like to see the data produced by the survey to be able to make the case for the program. The Total Cost of Care program has a goal to fund innovative programs.

Dr. Morhaim asked how you would quantify savings under the Total Cost of Care. Dr. Grant said that data has been provided to individual institutions to justify the programs.

Dr. Grant said that Medicare pays for medical services, symptom management, advance care planning. It does not pay for time spent discussing issues with the family or for social workers or chaplains. She indicated that one method of payment was bundled payment (set amount per month per patient) for all services needed for a

seriously ill patient. Medicare Advantage plans offer some supplementary benefits, but these are narrowly defined to limit costs.

Ms. Davis said that HSCRC does pay for Episodes of Care, but how would they be defined? Dr. Grant said that California and Hawaii have defined this, but it needs to be done on a state-specific basis.

Mr. Steffen said that he did not know how many Episodes of Care are defined. It would need to be conditionspecific. He also questioned how effective this would be in the absence of mandates.

Dr. Kearney said that there was a program that CareFirst funded and that would help to identify the most expensive patients. Dr. Bowlin said that this was an earlier program at CareFirst, but that is had been discontinued. Dr. Adams said that it is still being funded at MedStar. Dr. Bowlin said that she would look into it and do further research.

Dr. Grant also mentioned that the National Academy for State Health Policy (NASHP) is offering to help states develop palliative care programs by offering technical support to a few selected states who apply and are accepted. This does require buy in from several state agencies. She said that she would share this with MHCC staff.

Dr. Morhaim indicated that there needs to be demand from patients. He hoped that recent legislation on Advance Directives would help to identify and define palliative care. He would expect that an item to be checked would be to request a palliative care consult. Dr. Kearney stated that he has tried to sign up and that the process is challenging. Scott Brown of My Directives said that he appreciated the feedback.

### NEXT STEPS:

Ms. Davis asked MHCC staff to alert them when the survey was about to start, so that they can encourage participation among their members.

Ms. Cole said that the next step is implementation of the palliative care survey. The group will reconvene when there is data to share.

She thanked the group for a lively discussion and for their participation. She encouraged members to reach out by email if there are questions prior to the next meeting.