

Georgia Palliative Care and Quality of Life Council
Annual Report 2017

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Special Thanks to:

Lisa Marie Shekell

I. Review of Charges of the Advisory Council

We are pleased to share with you the Annual Report of the Georgia Palliative Care and Quality of Life Council for the fiscal year ending June 30, 2017. The Georgia General Assembly and Governor Deal establish the Council in 2016. The Council shall consult with and advise the Department of Community Health on matters related to the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in this state. Palliative care means those interventions which are intended to alleviate suffering and to achieve relief from, reduction of, or elimination of pain and of other physical, emotional, social, or spiritual symptoms of distress to achieve the best quality of life for the patients and their families. (31-7-191.7)

The Georgia Palliative Care and Quality of Life Advisory Council (GPCQOL) is charged with the following duties:

- Consult with and advise the Department of Community Health on matters related to the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in this state;
- Based on the results of this investigation, develop information on palliative care;

What is Palliative Care?

Palliative care is the relieving or soothing of symptoms of a disease or disorder while maintaining the highest possible quality of life for patients of all ages and with all conditions. Many people mistakenly believe you receive palliative care only when you can't be cured. Actually, palliative care can be provided alongside cure-directed therapies. Palliative care can help patients cope with illness by relieving symptoms—such as pain, anxiety, or loss of appetite—as patients sometimes experience while undergoing difficult medical treatments or procedures, such as surgery or chemotherapy. Palliative care is for people of any age and at any stage of a serious illness, whether that illness is curable, chronic, or life threatening. Financial coverage for palliative care varies. Palliative care providers are specially trained. They may provide palliative care through a hospital, outpatient office, hospice program, or both. Palliative care can be provided in the home, a hospital, nursing home, or assisted living facility. A palliative care team typically includes a palliative doctor, nurses, social workers, and other medical and nonmedical professionals and volunteers. The overall goal of palliative care is to improve the patient and their family's quality of life while seriously ill. Research shows that people often live longer when they receive palliative care along with other treatments that are targeted at their illness. There is a specific type of palliative care—called [hospice](#)—for people for whom a cure is very unlikely and who are likely to have 6 months or less to live. Hospice care can be provided at a hospice facility, hospital, nursing home or the individual's home.

How does Palliative Care differ from Hospice care?

To be eligible for hospice care, a physician expects the patient to have limited life expectancy of 6 months or less if the disease runs its usual course. Many patients receive hospice care and live much longer as a result, as treatment of the burdensome symptoms of illness have been shown to extend life. Even though patients who qualify for hospice care might benefit from hospice care sooner, unfortunately, most people don't receive hospice care until the final weeks or even days of life, possibly missing out on months of hospice support. In the state of Georgia, there are over 200 hospice agencies.

II. Inaugural Year Activities and Findings of the Council

Three in-person meetings of the Council were held on: November 10th 2016, December 15, 2016 and May 16, 2017. In the inaugural year of the Council, the Council's initial focus has been on understanding the state of Palliative Care in the State of Georgia and has begun to explore how the Council can best advance the care of patients with serious illness in our state. It was the consensus of the Council that Palliative Care is not well understood by the consumers. A key recommendation was to develop consumer-based education and awareness regarding Palliative Care.

At each in-person meeting, the Council received education by key leaders, stakeholders, and providers in the state on various important issues in the State:

- Status of Hospital Based Palliative Care in Georgia (Tammie E. Quest, MD, Emory Healthcare)
- Pediatric Palliative Care- an Overview (Khaliyah Johnson, MD, Children's' Healthcare of Atlanta)
- CMS Models of Palliative Care Aging and Special Populations, DCH (Marcy Alter, Department of Community Health)
- Consumer Registry for Hospice and Palliative Care in Georgia, Georgia Hospice and Palliative Care Organization (Paula Sanders, Executive Director, GHPCO)
- Palliative Care In-Action, Field Visit to the Outpatient Supportive Care Clinic and Visiting Nurse Inpatient Hospice @ Emory University Hospital

Summary Key Findings of Educational Sessions to the Council:

- *Status of Palliative Care in Georgia:*
 - Reviewed the definition of Palliative Care as it is known locally and nationally. Identified the gap that Palliative Care is often confused with Hospice Care. Review of the National Report Card and standing of Georgia's ratings in Palliative Care as determined by the Center to Advance Palliative Care with respect to reporting the prevalence of *hospital based palliative care services* available in the state. Current letter grade for the state of GA: "C". The National Report Card is a self-reported assessment of % of hospitals in the state with palliative care programs: A = >80%; B = 61-80%; C = 41-60%; D = 21-40%.
 - In the state of GA 32 of 58 hospital based programs report palliative care; by hospital type: Not for Profit - 66% (27/41); For Profit Hospitals - 11% (1/9); 50%

- (4/8); Sole Community Hospital Provider: 14% - (1/7); Hospitals over 300 beds
- 87% (20/23); Hospitals < 50 beds - 16% (3/19)

- *Pediatric Palliative Care an - Overview*

- Review of the Concurrent Care Model - Provision of the PPACA signed into law in March 2010 (section 2302) that makes hospice services available without forgoing any other services for which children would be available and applies specifically to Medicaid patients. Each state is responsible for implementing the federal mandate
- Pediatric Palliative Care in Georgia - Three hospital-based programs (Atlanta, Macon, Augusta)l one outpatient clinic program (Macon), one pediatric palliative care fellowship training position for physicians (Atlanta), variety of services offered at the community level (hospice and home-based care)
- Pediatric Hospice Care – most recent data 2012 reports - A survey querying 60+ hospices in the state of GA revealed that nearly half of hospices identified as pediatric providers. Over 60% of hospices felt most challenged by lack of pediatric volume and difficulty maintaining pediatric competency. Hospices felt most challenged by handling requests from pediatric families to continue life-sustaining therapies. Many hospices did not have an understanding of concurrent care. There are 12 hospices that currently provide pediatric hospice care. (Courtesy of Khaliah Johnson, MD, Children’s Healthcare of Atlanta)
- Current efforts to expand pediatric hospice care in Georgia include: current pilots with Medicaid approaches to billing and reimbursement for concurrent care; planning for updated pediatric needs assessment through Georgia Hospice and Palliative Care Organization; exploring ways for pediatric providers to remain connected and problem solve together (i.e.- monthly conference calls)

Pediatric hospice coverage



Children's Healthcare of Atlanta 

- CMS Models of Palliative Care Aging and Special Populations

- Review of CMS demonstration projects
- Overview given regarding the Medicare Care Choices Model (MCCM). This is a 2 year pilot project that mimics the Affordable Care Act for Children and concurrent care.

- The MCCM allows curative care to continue to when you one meets the eligibility for hospice election, but it does not have to elect hospice. MCCM allows you to continue to get palliative care through a participating demo site, which is a hospice agency that allow a palliative care concurrently with a curative care but you don't get the full array of hospice services. CMS will pay a Medicare hospice provider \$400 per member per month case management fee. Patients must certify for being eligible for hospice under the Medicare rules (terminal illness -6 months or less life expectancy).
- There are 142 hospices participating nationally. In the state of Georgia there is one hospice providers in MCCM: Compassionate Care Hospice of North Georgia (Athens)
- Consumer Registry for Hospice and Palliative Care in Georgia
 - Georgia would benefit from a Consumer Registry for Hospice and Palliative that provides Georgia consumers information, education and access to quality palliative care. Currently no such registry exists. Georgia Hospice and Palliative Organization would be willing to collaborate on creative solutions to create and maintain such a registry.
 - Key aspects to be determined for such a registry includes core elements, methods of updating and ensuring accuracy of such a registry.
- Palliative Care In-Action Session, Field Visit to the Outpatient Supportive Care Clinic and Visiting Nurse Inpatient Hospice @ Emory University Hospital
 - Met the desire of the Council to be better informed regarding the practice of adult Palliative Care in a complex setting
 - Heard from ground level providers of hospice and palliative care to include review of common cases seen in the outpatient palliative care setting at the Emory Healthcare Supportive Care Clinic with over 1,000 outpatient palliative care patients and to see an inpatient hospice facility

III. Advisory Council Recommends Key Areas of Focus Moving Forward

- Identification of good states to model our Georgia programs after so that we can utilize shared learning
- Expanded interaction of the Council more with communities and assist the providers in spreading the word about the services available key with linkages to Georgia's healthcare facility regulation divisions. Recommendations include formation of community stakeholders group that can inform the Council and DCH on important directions to include but not limited to: GHPCO, GHA, Georgia Hospital Association
- Connections with faith organizations as a vehicle for palliative care and hospice consumer information
- Formation of a Funded/Supported Registry - From a consumer standpoint, consumers should be able to see providers and exactly what companies and organizations provide in terms of palliative care with quality tracking. Recommendation that there be a linkage with databases such as ESP with over 23,000 resources listed statewide.

Recommendation that a registry taskforce will need to be convened. Taskforce will help to:

- Decide what information is most important to include in the registry.
 - Figure out what expenses may be involved in creating and maintaining the registry.
 - Determining a strategic approach to developing the registry.
- Continue to evaluate if more legislation is needed to strengthen and support palliative care across the state of Georgia with particular identification of possible opportunities for additional legislation that addresses children's issues