

2021 Update Report

State Palliative Care and Quality of Life Advisory Council

January 15, 2021

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Introduction

In 2018, the Tennessee State Palliative Care and Quality of Life Council was enacted as Public Chapter 955 (see Appendix A).

This act establishes an 11-member Palliative Care Advisory Council within the Tennessee Commission on Aging and Disability (TCAD). The purpose of the council is to (1) continually assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care and (2) provide recommendations to the governor and to the general assembly on issues related to its work.

The act, which became effective on April 24, 2018, requires the Council to begin annually reporting its findings and recommendations to the Governor and General Assembly. The first annual report was submitted beginning in January 2020. The Council members include health professionals having palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings such as acute care, long-term care, and hospice, and with a variety of populations, including pediatric and adult. The Council includes at least one (1) council member who is a board-certified hospice and palliative medicine physician, at least one (1) council member who is a licensed certified registered nurse practitioner with expertise in palliative care, and one (1) council member who is from the Tennessee Department of Health.

The Council submitted the State Palliative Care and Quality of Life Report in 2020. This report serves as an update.

What is Palliative Care?

Palliative care is specialized care for people facing *serious illness*¹, focusing on providing relief of suffering (physical, psychosocial, and spiritual), to maximize quality of life for both the patient and family.

1-Within palliative care, serious illness is defined as a health condition that carries a high risk of mortality and a) negatively impacts a person's daily function, b) negatively impacts a person's quality of life, and/or c) excessively strains the person's caregiver.

When is Palliative Care Appropriate?

Patients who are coping with a serious illness can benefit from palliative care at any time during their treatment. These patients may still be receiving treatment aimed at a cure. Palliative care is provided by a team of trained healthcare professionals who offer services such as:

- Providing relief from pain and other physical symptoms
- Improving quality of life
- Providing support to the seriously ill and the family and friends who love and care for them
- Assisting the patient, family and staff with medical decision-making

Palliative care works as a complimentary supplement to a patient's usual medical treatment and is available to patients at any stage of illness to help manage symptoms of their treatment.

Who Provides Palliative Care?

Doctors and nurse practitioners: evaluate and treat symptoms, assist with complicated medical conversations and situations, and will help establish goals of care that are consistent with beliefs, values, and wishes.

Case managers: provide resources and placement options and work with members of the primary team to coordinate home needs, nursing facility placements, or hospice support when appropriate.

Social workers: provide emotional and social support and help understand health care planning for the future, such as creating an advance care plan.

Pastoral care: maintaining the important role that faith and spirit play in the lives of patients.

Child life specialists: meet with children and their families to help discuss and understand difficult situations that a patient may face.

Pharmacy staff: ensure that prescriptions are accurate and assist in the acquisition of unusual or difficult-to-obtain medications necessary to treat symptoms.

Advisory Council Members

Justin Baker, MD, FAAP, FAAHPM, St. Jude Children's Research Hospital

Linda Estes, RN, BS, NHA, Tennessee Health Care Association

Karen Hyden, PhD, APN-BC, MSN/Ed, ACHPN, Compassus

Clay Jackson, MD, DipTh, West Cancer Center

Mohana Karlekar, MD, Vanderbilt University Medical Center

Maria Vilmerding Moore, Avalon Hospice/Curo Health Services, Kindred at Home

Kimberly Goessele, Alive Hospice

Jill Patterson, NP, University Palliative Care

Greg Phelps, MD, MPH. MAHCM, FAAHPM, Alleo Health Systems/Hospice of Chattanooga

Sally Pitt, Tennessee Department of Health

Tammy Stokes, BSN, CHPN, RN, Maury Regional Medical Center

Jim Shulman, JD, Tennessee Commission on Aging and Disability

Advisory Council Accomplishments to Date

Accomplishment 1 – Palliative Care Information and Education Program

The development and maintenance of a statewide Palliative Care Information and Education Program continues to be a priority for the council. In 2019, the council created an online directory of palliative care resources aimed at providers, patients, and caregivers. The webpage has had over 1,063 site visits from January 2019 – December 2020 (<https://www.tn.gov/aging/learn-about/palliative-care-advisory-council.html>).

Next, the Council developed a strategy to use online webinars to provide information on Palliative Care in Tennessee. The first webinar by Dr. Justin Baker provided an overview of Palliative Care in our state. Webinar recordings are published on the State Palliative Care Advisory Council website. Future webinar topics include Communication Strategies, Hospice vs. Palliative Care, Advance Care Directives, and more.

Accomplishment 2 – Statewide needs assessment survey

Another priority identified by members of the council was a needs assessment of the palliative care workforce including current availability, opportunities for leveraging existing non-palliative programs, and ways to deliver education and other supports to non-specialist providers. To address this goal, council members developed a survey tool modeled after a successful project in Florida. The survey tool was finalized and distribution began in late 2020. Full analysis and results will be completed in 2021. In addition, the council continues to promote the Center to Advance Palliative Care (CAPC) mapping process as a national tool to locate palliative care programs.

Accomplishment 3 – Partner with different members of the palliative care system

Another priority identified by members of the council was assessing the strengths, weaknesses, and needs of the palliative care workforce in Tennessee by partnering with different members of the palliative care system (clinicians, social workers, patient advocates, administration etc.) and the associations that represent these members. To address this goal, the council partnered with the Tennessee Department of Health and the Tennessee Hospital Association (THA) to implement a statewide Mentorship Program. This statewide program will pair those with expertise in palliative care with individuals interested in starting or expanding palliative care programs. This program slated to begin in early 2021 will address the council's goal of increasing access to palliative care.

Other Accomplishments

During 2020 the council also worked towards accomplishing other goals by presenting at local Rotary Clubs, the Tennessee Department of Health's CMP Program's Special Topics Webinar Series, and recording a podcast for a disaster preparedness agency.

Summary of Advisory Council Meetings and Statewide Palliative Care Conference

The Palliative Care Advisory Council met a total of four times between January 2020 and December 2020. Meetings were open and the public was encouraged to participate.

January 29, 2020

The council prioritized goals including education and community outreach. They developed strategies on how best to meet goals. Additionally, the council reviewed issues related to Advance Care Planning. This arose from discussions at the Palliative Care Conference in which individuals reported patients having confusion about Tennessee's Advanced Care Directive form. They discussed the possibility of a guide to help people understand the form. The group discussed different formats of the companion guide including print and online formats and useful ways to create and distribute. This guide will build upon successes of "Honoring Choices Tennessee."

July 29, 2020

The council heard a presentation by Dr. Matt Peachey, MD, Assistant Professor, Palliative Medicine Vanderbilt University Medical Center who presented pertinent information related to COVID-19. The council discussed federal and state regulations and how hospital-based palliative care programs are adapting with telehealth. Next, the council heard from the Tennessee Department of Health who presented "Tennessee Department of Health Guidance: Compassionate Care Visitation." The council discussed barriers and issues related to COVID-19 and working with vulnerable populations.

October 15, 2020

The council discussed recommendations to be included in the 2021 State Palliative Care and Quality of Life Update Report. Many of the 2020 goals were not met because priorities for Palliative Care Advisory Council members had to be COVID focused. Recognizing this, the council decided that each goal that wasn't met in 2020 should be focused on in 2021. The council heard updates on the statewide survey of Tennessee's palliative care system (clinicians, social workers, patient advocates, administration, etc.) to inform policy makers including the Governor and General Assembly, and to create a directory that is available to patients, their families and clinicians to improve access to palliative care. The survey is ready for dissemination. Each council member will receive the survey and are encouraged to share with anyone who can complete. Next, the statewide conference scheduled for October 2020 was postponed due to COVID-19 and rescheduled as a 2-day stakeholder meeting in April 2021. The stakeholder meetings will be focused on both pediatric palliative care (April 15) and adult palliative care (April 16). These stakeholder meetings are designed to be small with plenty of room for social distancing. The pediatric stakeholder meeting will focus on a strategic planning session and the kickoff for the TN Palliative Care Pediatric Coalition. The adult palliative care stakeholder meeting will be facilitated, and attendees will be given the opportunity to talk strategy of how to grow Palliative Care across the state. All Council members were asked to "Save the Dates." Finally, the Mentor/Mentee program is a new initiative by Tennessee Hospital Association with funding from Tennessee Department of Health. This program will pair those with expertise in palliative care with individuals across the state who are

interested in starting or expanding palliative care programs. This program will help this council meet one of its goals to increase access to palliative care. Council members with capacity will serve as Mentors in the program.

Palliative Care and COVID-19

Palliative care focuses on improving quality of life for people living with a serious illness, including COVID-19. Palliative care specialists' expertise in symptom management and skilled communication is essential to the care of people with COVID-19. The palliative care patient population—those living with serious illness—are in the highest risk group for COVID-19, and they and their loved ones are not only particularly vulnerable but also particularly stressed by the current situation¹.

We are grateful to all the palliative care teams in the state who are leading their colleagues so that they can rapidly enhance and deploy best practices in communication and symptom management. This council is made up of palliative care providers and advocates who are serving on the front lines during this pandemic. While the council made every effort to meet the recommendations, some were not met because priorities for Palliative Care Advisory Council members had to be COVID-19 focused. Recognizing this, the Council decided that each goal that wasn't met in 2020 should be focused on in 2021.

¹[COVID-19 Response Resources Hub | Center to Advance Palliative Care \(capc.org\)](#)

Recommendations

Recommendation 1. In recognition of confusion surrounding the definition of palliative care and fundamental differences between palliative care and hospice care, adopt the Council-approved definition of palliative care, in order to provide clarity and education to healthcare practitioners and the public.

2019

Strategy a. Review definitions developed and adopted by other state and national groups
Complete. After reviewing other state and national definitions, the council developed a state specific definition. This definition was adopted by the State Palliative Care and Quality of Life Advisory Council on January 30, 2019.

Strategy b. Codify definition where appropriate

Complete. This definition provided the framework for the definition of palliative care in Public Chapter 124 of 2019.

Strategy c. Facilitate cross-sector standardization of definition

Complete. This definition was incorporated into multiple formal state guidelines and plans.

Recommendation 2: Ensure access to comprehensive and accurate information on palliative care available to the public, health care providers, and health care facilities through the development and maintenance of a statewide Palliative Care Outreach and Information.

2019

Strategy a. Create an online directory of palliative care resources.

Complete. The Commission on Aging and Disability has an information page on their website with palliative care definition, reports, and resources.

Strategy b. Update the online directory of palliative care resources.

Ongoing. The council provides updated resources to the website on a yearly basis.

Strategy c. Develop an outreach plan to increase communication with providers, patients, families, and caregivers

Complete. The council developed an outreach plan to include increased education and participation.

Strategy d. Plan a statewide conference focused on palliative care including pediatric and community based palliative care.

Complete. In 2019, the council partnered with Tennessee Hospital Association (THA), Department of Health (TDH), and 15 other organizations interested in assessing the status of palliative care to plan and host a statewide conference focused on palliative care.

Ongoing. The conference took place Sept 27, 2019 with over 115 attendees with interdisciplinary backgrounds representing east, middle, and west Tennessee. The 2020 State Palliative Care Conference was originally scheduled for September 18, 2020, but was canceled due to COVID-19.

2020

Strategy a. Include in the palliative care resource directory information on multiple aspects of goals of care including examples of the POST form and Power of Attorney.

Strategy b. Develop a communication toolkit to be shared with associations specializing in chronic conditions.

Strategy c. Host palliative care presentations and trainings statewide.

Ongoing. The Council members provided at least one presentation related to palliative care (target audience includes those who don't work directly in palliative care) and reported presentation date, location, and audience to TCAD staff.

Strategy d. Increase attendance and opportunities for comments and/or presentations from community members during Palliative Care Advisory Council meetings

Complete. By April 2020, the council compiled a list of organizations TCAD staff can reach out to and invite. Ongoing. TCAD staff will continue to reach out and update this list.

2021

Strategy d. Increase attendance and opportunities for comments and/or presentations from community members during Palliative Care Advisory Council meetings. (cont.)

Ongoing. By December 2021, each Council member will recruit 3 guests to attend quarterly meetings.

Strategy e. Increase attendance and opportunities for comments and/or presentations from faith-based and clergy representatives during Palliative Care Advisory Council meetings

Ongoing. By July 2021, Council members will develop a specific strategy to reach out to at least three faith-based and clergy representatives to inform them of Council work and invite to future meetings. This strategy will build upon local partnerships like the recent Book of Life Conference.

Ongoing. By December 2021, Council members will have one presentation from faith-based group.

Recommendation 3. Partner with the different members of the palliative care system (clinicians, social workers, patient advocates, administration etc.) and the associations that represent these members to assess the strengths, weaknesses, and needs of the palliative care workforce in Tennessee.

2020

Strategy a. Research strategies to leverage existing non-palliative programs to meet needs and/or deliver education and support to non-specialist providers.

Ongoing. The council utilized the provider survey to help identify gaps and non-palliative programs that could potentially meet the needs and/or deliver education and support to non-specialist providers.

Strategy b. Formalize new partnerships with organizations interested in the status of palliative care, including barriers to care, in Tennessee.

Strategy c. Encourage provider participation in the CAPC Mapping process to make it easier for patients, families, and providers to locate palliative care programs.

Strategy d. Promote palliative care among primary care.

Ongoing. Utilizing statewide survey data, By August 2021, TCAD staff will compile a list of local, regional, and statewide organizations, associations, and conferences for primary care physicians.

Ongoing. By December 2021, Council members will create action plan for connecting with these entities

Strategy e. Identify and partner with palliative care “champions” in rural and underserved communities.

Ongoing. After the 2021 stakeholder conference, each Council member will identify one (1) palliative care champion from rural and underserved communities.

Ongoing. By December 2021, each Council member will invite “champion” to either Statewide PC Conference or future meeting.

Strategy f. Invite representatives from hospital-based finance departments to attend and/or participate in Council meetings.

Ongoing. After the 2021 stakeholder conference, each Council member affiliated with a hospital will identify and submit contact information for a member of hospital-based finance departments to invite to Statewide PC Conference.

Recommendation 4: Communicate directly with the different members of the palliative care system (clinicians, social workers, patient advocates, etc.) and the associations that represent these members to assess the strengths, weaknesses, and needs of the palliative care workforce in Tennessee.

2020

Strategy a. Research what specialty palliative services are currently available, opportunities for leveraging existing non-palliative programs to meet needs, and how to deliver education and other supports to non-specialist providers.

Strategy b. Partner with other organizations interested in assessing the status of palliative care, including barriers to care, in Tennessee.

2021

Strategy c. Encourage participation in the CAPC Mapping process to make it easier for patients, families, and providers to locate palliative care programs.

Ongoing. By April 2021, TCAD staff will compile and distribute to Council members an abbreviated list of Tennessee organizations participating in CAPC mapping.

By July 2021, Council members will review list of participating organizations to identify organizations not participating.

Strategy d. By December 2021, TCAD staff and/or Council members will meet with programs not participating in CAPC mapping to assess barriers to and opportunities for participation

Recommendation 5: Explore potential funding opportunities for projects to advance palliative care and quality of life for Tennesseans including, but not exclusive to, federal grants, state funded graduate medical education, or quality improvement grants.

2020

Strategy a. Research and identify potential grants and other funding sources.

Ongoing. TCAD will regularly emails Council members potential grants and funding opportunities related to palliative care

2021

Strategy b. Identify, track, and report data related to palliative care and overall care quality
Ongoing. By April 2021, TCAD staff will compile list of potential data sources for review by Council.

Strategy c. Partner with stakeholders throughout the state of Tennessee to draft and develop measurable and scalable evidence-based palliative care initiatives.

Recommendation 6. Study and understand current payment models and their impact on health care costs surrounding the use of palliative care in the state of Tennessee.

2021

Strategy a. Technical assistance provided to plans should include instruction in different methods for assessing palliative care programs' impact on health care utilization and total health care cost analyses.

Strategy b. Develop and study alternate payment models in order to allow palliative care to be more accessible to additional providers and patients

Appendix A



State of Tennessee

PUBLIC CHAPTER NO. 955

HOUSE BILL NO. 2118

By Representatives Kumar, Weaver, Powell, Beck, Carter, Gilmore, Favors, Whitson, Cooper, Thompson, Terry, Akbari, Camper, Moody, Turner

Substituted for: Senate Bill No. 2561

By Senators Hensley, Massey, Briggs, Crowe

AN ACT to amend Tennessee Code Annotated, Title 4, Chapter 29 and Title 71, Chapter 2, relative to palliative care.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Section 4-29-244(a), is amended by adding the following as a new subdivision:

() State palliative care and quality of life council, created by § 71-2-115;

SECTION 2. Tennessee Code Annotated, Title 71, Chapter 2, Part 1, is amended by adding the following as a new section:

71-2-115.

(a) As used in this section:

(1) "Commission" means the Tennessee commission on aging and disability;

(2) "Council" means the state palliative care and quality of life council;

(3) "Executive director" shall mean the executive director of the Tennessee commission on aging and disability; and

(4) "Palliative care" means an approach that improves the quality of life of patients and their families facing the problems associated with chronic life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care includes, but is not limited to:

(A) Discussions involving a patient's goals for treatment;

(B) Discussions involving treatment options that are appropriate to the patient, including, where appropriate, hospice care; and

(C) Comprehensive pain and symptom management.

(b) The state palliative care and quality of life advisory council is established.

(c) The purpose of the council is to continually assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care. The council shall provide recommendations to the governor and to the general assembly on issues related to its work.

(d) The council membership shall be appointed by the executive director, after consulting with Tennessee Hospice Association, Tennessee Hospital Association, Tennessee Medical Association, Tennessee Nursing Association, Tennessee Health Care Association, Tennessee Association of Home Care, and the Tennessee Chapter of American Cancer Society, and shall include interdisciplinary palliative care medical,

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nursing, social work, pharmacy, and spiritual professional expertise; patient and family caregiver advocate representation; and any other relevant appointees the executive director determines appropriate. The advisory council shall consist of no more than eleven (11) members. The executive director shall consider the racial, geographic, urban/rural, and economic diversity of the state when appointing members. Membership shall specifically include health professionals having palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings such as acute care, long-term care, and hospice, and with a variety of populations, including pediatric, youth, and adult. At least one (1) council member shall be a board-certified hospice and palliative medicine physician, at least one (1) council member shall be a licensed certified registered nurse practitioner with expertise in palliative care, and one (1) council member shall be from the department of health. Council members shall be appointed for a term of three (3) years. The members shall elect a chair and vice chair, whose duties shall be established by the council. The council shall fix a time and place for regular meetings and shall meet no less than twice yearly.

(e) Council members shall receive no compensation for their services or travel reimbursement for attending meetings.

(f) The council shall consult with and advise the executive director on matters related to the establishment, maintenance, and operation of palliative care initiatives in this state.

(g) The commission shall provide administrative support to the council.

(h) By January 15th of 2020, and by January 15 of each subsequent year, the advisory council shall submit a report to the general assembly that addresses barriers to palliative care access, analyzes service utilization data, and provides recommendations and best practices to address gaps in service.

SECTION 3. This act shall take effect upon becoming a law, the public welfare requiring

it.

HOUSE BILL NO. 2118

PASSED: April 24, 2018



BETH HARWELL, SPEAKER
HOUSE OF REPRESENTATIVES



RANDY MCNALLY
SPEAKER OF THE SENATE

APPROVED this 15th day of May 2018



BILL HASLAM, GOVERNOR

This report was prepared by the Tennessee Commission on Aging and Disability.