



# 2022

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State Palliative Care and Quality  
of Life Advisory Council Report



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**STATE OF TENNESSEE  
COMMISSION ON AGING AND DISABILITY**

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James Dunn  
Executive Director

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January 15, 2022

The Honorable Rusty Crowe  
425 Rep. John Lewis Way N.  
Suite 720 Cordell Hull Bldg.  
Nashville, TN 37243

The Honorable Bryan Terry  
425 Rep. John Lewis Way N.  
Suite 646 Cordell Hull Bldg.  
Nashville, TN 37243

Dear Chairmen Crowe and Terry:

Public Chapter 955 (2018) passed by the General Assembly established the State Palliative Care and Quality of Life Advisory Council (“Council”) and administratively attached the Council to the Tennessee Commission on Aging and Disability (TCAD). The purpose of the Council is to assess the status of palliative care in Tennessee and identify barriers that prevent such care from being obtained by those who could benefit from it.

The Act also requires an annual report be submitted to the General Assembly detailing efforts of the Council, as well as, laying out recommendations to address palliative care needs across the state.

Enclosed please find a copy of the updated report which accounts for Council actions throughout 2021 and proposes to carry over the Council’s goals and recommendations from the previous report submitted in January 2021.

If you have questions or would like to discuss any aspect of the report, please contact Mason Devers, Communications Director and Legislative Liaison, [Mason.Devers@tn.gov](mailto:Mason.Devers@tn.gov) or Robb Cagle, Legislative Liaison, [Robb.Cagle@tn.gov](mailto:Robb.Cagle@tn.gov).

Sincerely,

A handwritten signature in black ink that reads "James Dunn". The signature is written in a cursive style with a large, looping initial "J" and a long, horizontal flourish at the end.

James Dunn  
Executive Director

## **Background**

### ***Council History and Purpose***

The Tennessee State Palliative Care and Quality of Life Council was enacted as part of Public Chapter 955 (2018). *See Appendix A*.

The Act established an 11-member Council administratively attached to 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 requires annual reports of its findings and recommendations to the General Assembly. The first annual report was submitted in January 2020 and a subsequent report was submitted in January 2021<sup>1</sup>. This report serves as an update to the January 2021 report.

### ***Advisory Council Members***

Pursuant to state statute, the Council members include health professionals who have 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. The members also have experience providing palliative care with both pediatric and adult patients.

The following individuals constitute the makeup of the Council:

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

Nina Monroe, RN, BSN, NHA, Tennessee Health Care Association

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

Clay Jackson, MD, DipTh, West Cancer Center

Mohana Karlekar, MD, Vanderbilt University Medical Center

Maria Vilmerding Moore, Kindred at Home

Kimberly Goessele, Alive Hospice

Jill Patterson, NP, University Palliative Care

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<sup>1</sup> <https://www.tn.gov/content/dam/tn/aging/documents/2021%20Palliative%20Care%20Update%20Report.pdf>

Greg Phelps, MD, MPH. MAHCM, FAAHPM, Covenant Health

Sally Pitt, Tennessee Department of Health

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

Executive Director James Dunn, Tennessee Commission on Aging and Disability

## **Introduction to Palliative Care**

### ***What is Palliative Care?***

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

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; and
- 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 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.

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. Subsequent webinar topics include Communication Strategies, Hospice vs. Palliative Care, Advance Care Directives, and more. Webinar recordings are published on the Council's website<sup>2</sup>.

### ***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.

### ***Accomplishment 3 – Partnering Within the Palliative Care System***

#### **2020**

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

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<sup>2</sup> <https://www.tn.gov/aging/resource-directory/palliative-care-advisory-council.html>

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 (“TDH”) and 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. The program is slated to begin in early 2021.

## 2021

The mentoring program commenced in 2021 and was a partnership between the Council, TCAD, TDH, and THA. Together, the organizations created a toolkit for mentees and mentors consisting of topics including: an overview of palliative care; etiquette and team dynamics; communication techniques; advance care directives; and making the case for palliative care. Mentees and mentors met one hour per month for six months. Participants included 40 mentees and 12 mentors from areas across the state. Mentors and mentees both reported that they would like to continue this program, however, a lack of funding for the program has prevented further implementation. The membership program was initially funded through dollars from TDH, and additional funding has not yet been secured.

### ***Accomplishment 4 – Palliative Care Summit***

In April 2021, THA hosted a state-wide virtual summit focused on discussing and expanding pediatric and adult palliative care education and awareness in Tennessee. Much of the Council attended/presented at the summit. During the summit, attendees discussed barriers to palliative care. One barrier discussed was lack of education. Potential strategies to address this barrier included: the development of a mentoring program; videos to be shared and disseminated across geographic areas; “lunch and learns” to foster relationship building; and increasing access to virtual education opportunities. At the summit and Council meetings, the members discussed strategies to get other stakeholders involved to bridge partnerships across disciplines and creating a centralized resource directory for providers. Additionally, the group discussed the successful outreach efforts of the Purple Cities Alliance, a team of local volunteers, practitioners, and community leaders leading an initiative in Knoxville to make it a “dementia friendly city.” The Purple Cities Alliance provides dementia education and training resources that enable community members and organizations to become more dementia friendly. The Council suggested using similar strategies for Palliative Care outreach and education.



## **Summary of Advisory Council Meetings**

### ***2020 Council Meetings***

The Council met a total of four times between January 2020 and December 2020. Meetings were open to the public 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 advanced care planning. This arose from discussions at the Palliative Care Conference in which individuals reported patients having confusion about the 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.

Finally, the Mentor/Mentee program is a new initiative by Tennessee Hospital Association. 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 the Council meet one of its goals to increase access to palliative care. Council members with time availability will serve as mentors in the program.

### ***2021 Council Meetings***

Due to a change in administration at TCAD, ensuing staff changes, and the COVID-19 pandemic, the Council was only able to meet twice during 2021.

#### July 23, 2021

The Council heard a presentation from Adrienne Nordman, Assistant Vice President of Member Relations and Education at the Tennessee Hospital Association, who reviewed the involvement of THA with the Palliative Care Advisory Council. This included a grant from TDH and the inaugural year of the Palliative Care Mentoring Program.

Next, Dean Thompson of the Tennessee Hospice and Palliative Care Organization provided an update on their advocacy and education. This overview included an update on recently passed Certificate of Need legislation and the upcoming National Hospice and Palliative Care Organization Interdisciplinary Conference to be held in Memphis September 20-22, 2021.

Dr. Justin Baker, Dr. Tracey Hills, and Dr. Mohana Karlekar spoke on the discussions that took place at the Palliative Care Summit held in April. Conversations by attendees focused on identifying existing barriers to providing palliative care access.

Sally Pitt provided members an overview of the Purple Cities Alliance and the Dementia Friendly Community Initiative.

December 28, 2021

The Council discussed recommendations to be included in the 2022 State Palliative Care and Quality of Life Update Report. Many of the 2021 goals were not met because priorities for Council members had been COVID focused. Recognizing this, the Council decided that each goal that wasn't met in 2021 should be focused on in 2022.

## **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 affected by the COVID-19 coronavirus. The palliative care patient population—those living with serious illness—are in the highest risk group for COVID-19.

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.

## **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 (2019).

**Strategy C.** Facilitate cross-sector standardization of definition of palliative care.

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 state-wide conference focused on palliative care including pediatric and community-based palliative care.

Complete. In 2019, the Council partnered with THA, TDH, and 15 other organizations interested in assessing the status of palliative care to plan and host a state-wide 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. The 2021 state-wide conference was held virtually in April, and another state-wide conference is planned for April 2022 and will be hosted by THA.

## **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 (

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

**Strategy C.** Host palliative care presentations and trainings state-wide.

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.

**2021/2022**

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

Ongoing. By December 2022, 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 2022, 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.

Ongoing. By December 2022, 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 Center to Advance Palliative Care (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 2022, TCAD staff will compile a list of local, regional, and statewide organizations, associations, and conferences for primary care physicians.

Ongoing. By December 2022, 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 2022, 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 Palliative Care 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.

## 2021/2022

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

**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 email Council members potential grants and funding opportunities related to palliative care.

**2021/2022**

**Strategy B.** Identify, track, and report data related to palliative care and overall care quality Ongoing. By December 2022, TCAD staff will explore and possibly compile a 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.

**2021/2022**

**Strategy A.** Ongoing. 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.** Ongoing. 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,



**HB 2118**

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 15<sup>th</sup> day of May 2018

  
\_\_\_\_\_  
BILL HASLAM, GOVERNOR