



Palliative Care Advisory Council

ANNUAL LEGISLATIVE REPORT

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Minnesota Palliative Care Advisory Council Annual Legislative Report

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Introduction to the Palliative Care Council

The Minnesota Legislature established the Minnesota Palliative Care Advisory Council (the Council) in 2017 under Minnesota Statutes, section 144.059. The Council is charged with assessing, analyzing, and making recommendations to the legislature on issues related to palliative care in Minnesota.

The Council is tasked with:

- 1. assessing the availability of palliative care in Minnesota,*
- 2. analyzing barriers to greater access to palliative care, and*
- 3. recommending language for legislative action with draft legislation to implement the recommendations.*

The Council is made up of a variety of professionals who have palliative care work experience or expertise in palliative care delivery models. They come from a variety of inpatient, outpatient, and community settings, like acute care, long-term care or hospice. They work with a variety of patients from pediatric to youth and adults. In addition, there are several positions on the council who provide a patient or caregiver perspective. Each Council position is active for three years.

Current council positions include:

- Care Coordinators (2)*
- Health Plan Representative*
- Licensed Health Professionals (3)*
- Member (at large) (2)*
- Patient or Personal Caregiver (4)*
- Physician (2)*
- Physician Assistant*
- Registered Nurse or Advance Practice Nurse (2)*
- Licensed Social Worker*

Prospective council member applications are reviewed by the Minnesota Department of Health, with final selections appointed by the current Commissioner of Health.

The Council is required to report on its progress by February 15 of each year. Prior Council legislative reports can be found on the Minnesota Department of Health for the Palliative Care Advisory Council.¹

The following pages present the Council's summary of work efforts during 2022, outline the work to be undertaken during 2023, and highlight concerns for health care for Minnesotans in the coming years, and show why palliative care is a core element of the solution to rising health care costs.

¹ Minnesota Department of Health. (n.d.) *Palliative Care Advisory Council*. Retrieved November 4, 2022, from <https://www.health.state.mn.us/people/palliative/pcac.html>

Executive Summary

Minnesota is facing challenges in health care today – and those challenges are predicted to become a perfect storm as several health care indices converge by the end of this decade. Minnesota is facing an aging population that is living longer -- resulting in more patients living with serious or terminal illnesses, fewer available family caregivers, fewer long-term care facilities, and fewer physicians and nurses available to provide health care for Minnesota's population.

The statistics for the impending health care crisis are alarming for both Minnesota and the country:

- **An aging population.** By 2033, the Minnesota's forecasted population age 65+ is projected to be 1.3 million-- a 31% increase from 2021. This population is expected to be 20% of Minnesota's total population.¹
- **People are living longer with less money and fewer family supports.**² The population of older adults, as well as people with complex physical needs, is also growing.³ In 2000, the United States had 4.2 million people age 85 and older – by 2050 it will be 18 million, a 231% increase.⁴ For millions of Americans, their family members are now widely scattered, working full-time, or otherwise unavailable to care for a loved one living with a serious illness or terminal condition.⁵
- **Health Disparities.** Ninety percent of hospitals with palliative care are in urban area. Only 17% of rural hospitals with fifty or more beds report palliative care programs. Access to palliative care continues to remain variable and depends more upon accident of geography, whether a hospital is for-profit or nonprofit, and hospital size than it does upon the needs of patients living with a serious illness, and their families.⁶

In addition, a large body of research documents disparities in the assessment and treatment of pain for African Americans and Hispanics versus Whites across age groups, diagnoses, and settings, with similar trends for Asians and Native Americans in nursing homes.⁷

- **Fewer long-term care facilities.** Since 2019, 18 Minnesota nursing homes have closed, including 6 in 2022.⁸ As the population continues to grow and age, more seriously ill and frail terminal or elderly patients will need more family and community supports.⁹ An estimated 70% of people currently turning 65 will require long-term care in their lifetime, and they will receive care for an average of 3 years.¹⁰
- **Fewer, and aging, physicians in rural Minnesota.** According to a 2019 report on health care in rural Minnesota, the average age of physicians in rural Minnesota is about 55. In the Twin Cities area, there is approximately 1 physician for every 750 people; in the northwest quadrant of Minnesota, there is only one physician for every 1,500 people.¹¹
- **Nursing shortage.** According to a report from the National Institutes of Health, the nursing shortage, which started before COVID, is forecasting that shortages of registered nurses (RNs) will continue to grow to a more than 510,000 RN gap by 2030.¹² While the number of RNs is expected to increase about 9 percent by 2030,¹³ the percentage growth of RNs is still less than the percentage growth of the population age 65 and older for the same period.
- **Patients are discharged from hospitals to homes that are unprepared to receive them.** The Health Services Advisory Group identified the first of 37 typical failures in discharge planning as “Failure to actively include the patient and family caregivers in identifying needs and resources and planning for the discharge. Caregivers were not involved in the medical and discharge decision making process.”¹⁴

Since the 1980's, hospitals and payers have reduced acute care costs by shortening length of stay and shifting care into the home and community, with individuals with serious illness becoming more dependent on family caregivers to address gaps in care. Increasingly, family caregivers need to have a sophisticated understanding of the patient's condition and acquire skills to execute complex medical/nursing tasks, previously performed only by skilled providers in institutional settings. They often receive little training or ongoing support for these unfamiliar and demanding responsibilities.¹⁵

The good news? Palliative Care is one of the solutions! It is uniquely positioned to lean into the current and predicted health care challenges and provide that extra layer of support for those directly involved with patients of any age living with serious illnesses/conditions and the terminally ill – the patients themselves, their caregivers, and their physicians.

Patients and their caregivers – who receive **early palliative care support** -- have **significantly improved outcomes, lower stress burden and depression, and higher quality of life.**¹⁶

Palliative care offers a high-value approach to combating the existing costly and often undesirable care options (repeated and unwanted hospitalizations and skilled nursing facility admissions, unnecessary emergency department visits, and panicked 911 calls). **The evidence is clear: to deliver high-quality, responsive care for our most complex patients, investment in reliable access to palliative care in America's health care system is required.**¹⁷

This report provides an update to the Council's four actionable policy recommendations set forth in the Council's 2022 annual legislative report,¹⁸ and includes updates from Council's Education, Training, and Awareness workgroup, and the Diversity, Equity, and Inclusion workgroup.

¹ Minnesota Compass. (2022). All Minnesotans. [Data file and documentation]. Retrieved from <https://www.mncompass.org/topics/demographics?age#1-5229-g>

² Minnesota Leadership Council on Aging. Retrieved from <https://www.mnlcoa.org/agenda>

³ RAISE Family Caregiving Advisory Council. (2022). Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregiver Act: Initial Report to Congress. Retrieved from https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf, pg 56

⁴ Lynn, Joanne, MD. (2016). *MediCaring Communities: Getting What We Want and Need In Frail Old Age at an Affordable Cost*. [Kindle edition]. Available from Amazon.com, Kindle location 119

⁵ *Ibid.*

⁶ Center to Advance Palliative Care (CAPC). 2023. Retrieved from <https://www.capc.org/blog/increasing-awareness-palliative-care-minorities/>

⁷ Johnson, Kimberly, MD, MHS (2013) Racial and Ethnic Disparities in Palliative Care. *Journal of Palliative Medicine*. Volume 16 Number 11.

⁸ Cox, Peter. (2022, October 5). Fears, frustration mount as Minnesota's long-term care staffing crisis deepens. *MPRNews*. Retrieved from <https://www.mprnews.org/story/2022/10/05/fears-frustration-mount-as-minnesotas-longterm-care-staffing-crisis-deepens>

⁹ Lynn, Joanne, MD. (2016). *MediCaring Communities: Getting What We Want and Need In Frail Old Age at an Affordable Cost*. [Kindle edition]. Available from Amazon.com, Kindle location 119

¹⁰ PHCA. (2022). Retrieved from <https://www.phca.org/for-consumers/research-data/long-term-and-post-acute-care-trends-and-statistics#:~:text=Long-Term%20Care%20Statistics%201%20Most%20people%20will%20need,for%20an%20average%20of%203%20years.%20More%20items>

¹¹ Picone, Linda. (2019, September-October). Health Care in Rural Minnesota: Fewer physicians and challenges ahead – but commitment to care. *Minnesota Medicine*. Retrieved from [https://www.mnmed.org/getattachment/news-and-publications/mn-medicine-magazine/Past-Issues/Past-Issues-2019/Sept-Oct-2019/Pages-from-Feature-Healthcare-in-Rural-MN-2-\(2\).pdf.aspx?lang=en-US](https://www.mnmed.org/getattachment/news-and-publications/mn-medicine-magazine/Past-Issues/Past-Issues-2019/Sept-Oct-2019/Pages-from-Feature-Healthcare-in-Rural-MN-2-(2).pdf.aspx?lang=en-US), pg 11

¹² Booher, Miranda, RN. (2019, December 21). Re: 23 Nursing and Healthcare Staffing Trends to Watch for in 2022. [Web log post]. Retrieved from <https://nursa.com/blog/healthcare-staffing-trends-for-2022/>

¹³ *Ibid.*

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- ¹⁴ RAISE Family Caregiving Advisory Council. (2022). Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregiver Act: Initial Report to Congress. Retrieved from https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf, page 93
- ¹⁵ Bell, Whitney, and Young. (2019). Family Caregiving in Serious Illness in the United States: Recommendations to Support an Invisible Workforce. *Journal of the American Geriatrics Society*. Volume 67, Issue S2. Retrieved from <https://doi.org/10.1111/jgs.15820>
- ¹⁶ Dioanne-Odom, et al. (2015, March 23). Benefits of Early Versus Delayed Palliative Care to Information Family Caregivers of Patients With Advanced Cancer: Outcomes from the ENABLE III Randomized Controlled Trial. *Journal of Clinical Oncology*. Retrieved from <https://ascopubs.org/doi/10.1200/JCO.2014.58.7824>
- ¹⁷ CAPC. 2023. https://reportcard.capc.org/wp-content/uploads/2020/05/CAPC_State-by-State-Report-Card_051120.pdf
- ¹⁸ Minnesota Palliative Care Advisory Council. (2022). Annual Legislative Report. Retrieved from <https://www.health.state.mn.us/people/palliative/docs/pcalegreport2022.pdf>

Definition of Palliative Care

Recommended Action #1 from the 2022 Annual Legislative Report: Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session (2022) for action.

UPDATE: COMPLETED.

Definitions matter. An accurate definition of palliative care clarifies and provides the foundation for developing core services and benefits. An inaccurate definition, however, creates confusion, suspicion, and leaves interpretation up to the reader, resulting in patients and/or family caregivers not receiving the comprehensive supportive care they need.

Creating an accurate palliative care definition for Minnesota was the Council's top priority for the 2022 legislative session.

The Council is pleased to announce the bill modifying Minnesota's definition of palliative care, found in [Statute 144.75A Subd. 12](#), was **approved** by both the House and Senate this year and was signed into law **effective August 1, 2022**.

Palliative care in Minnesota is now defined as:

“Palliative care” means specialized medical care for people living with a serious illness or life-limiting condition. This type of care is focused on reducing the pain, symptoms, and stress of a serious illness or condition. Palliative care is a team-based approach to care, providing essential support at any age or stage of serious illness or condition, and is often provided together with curative treatment. The goal of palliative care is to improve quality of life for both the patient and the patient’s family or care partner.”

While the Council celebrates the success of achieving this milestone, the Council also recognizes that this modified definition still exists within the current state statute defining hospice.

The work of the Council cannot be considered done until palliative care is a stand-alone statute within Minnesota regulations.

The Council recognizes that confusing definitions and differences in palliative care benefits are key barriers for patients and their caregivers who are eligible to receive palliative care.

Confusion continues to exist regarding what palliative care is – and isn't – at many levels, *e.g., state, federal, medical communities, and home-based communities.*

In particular, palliative care continues to be mistakenly associated with hospice care only and considered a benefit only for persons who are terminally ill.

While this has now been corrected in Minnesota Statute, the Council was surprised to read the following statement in the recently distributed Medicare & You 2023 guide sent to Medicare recipients:

“To qualify for hospice care, a hospice doctor and your doctor (if you have one) must certify that you're terminally ill, meaning you have a life expectancy of 6 months or less. When you agree to hospice care, you're agreeing to comfort care* (palliative care) instead of care to

cure your terminal illness. You also must sign a statement choosing hospice care instead of other Medicare-covered treatments for your terminal illness and related conditions.”¹

The Center for Medicare & Medicaid Services (CMS) defines “terminally ill” as occurring when the patient has been diagnosed with a medical condition that reduces their life expectancy and the patient is near the end of life. While Medicare uses the “have a life expectancy of 6 months or less” as the criteria to qualify for hospice, each state can decide the criteria used for “life expectancy” in order to receive hospice care under Medicaid.²

Minnesota defines “terminally ill” in Statute 144A.75, Subd. 6.: Hospice patient as:

(1) has been diagnosed as **terminally ill, with a probable life expectancy of under one year**; or

(2) **is 21 years of age or younger; has been diagnosed with a chronic, complex, and life-threatening illness contributing to a shortened life expectancy; and is not expected to survive to adulthood.**

The preceding paragraphs highlight how easily palliative care is confused with hospice or “comfort care only” care plans. In reality, palliative care should be a benefit available to any patient living with serious illness/condition, or with a terminal illness, with supportive care available not only to the patient, but also their caregivers, while also providing an extra layer of support to the patient’s physician.

Palliative care can provide patients relief from symptoms like pain, anxiety, shortness of breath, fatigue, and other challenges that are the results of a chronic or serious condition, and the treatments for that condition. The benefits of palliative care not only help the patient, but also their families and the medical system.³

**(Note: “Comfort care” is generally defined as managing the patient’s pain and symptoms but is not providing curative care. Curative care is intended to cure the patient and goes beyond just managing pain and symptoms).*

¹ Center for Medicare and Medicaid Services. (2022). Medicare & You 2023: The Official U.S. Government Medicare Handbook. CMS. Pg 26

² Center for Medicare and Medicaid Services. (2016). Hospice Toolkit: An Overview of the Medicaid Hospice Benefit. CMS. Retrieved from <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/hospice-overviewbooklet.pdf#:~:text=%E2%80%9CTerminally%20ill%E2%80%9D%20means%20the%20patient%20has%20been%20diagnosed,must%20have%20to%20receive%20hospice%20care%20under%20Medicaid> pg 3

³ Minnesota Department of Health. Palliative Care. Retrieved November 4, 2022, from <https://www.health.state.mn.us/people/palliative/index.html>

Palliative Care Core Services

Recommended Action #2 from the 2022 Annual Legislative Report: Draft a recommended core set of palliative care services for Minnesota.

UPDATE: In progress. A recommended palliative care core services has been developed and will be presented to stakeholders for additional feedback during 2023.

Using the definition approved and signed into law, the Council focused their efforts on defining and recommending a set of core services for palliative care. Recommendations include:

- Who is eligible to receive palliative care services
- Where palliative care can be provided, e.g., care settings
- Who is part of the medical interdisciplinary team (IDT)
- What medical and supportive needs means
- How the core services may be structured in a tiered benefit which supports and maximizes a variable payment and reimbursement model

Palliative Care Eligible Population

The Council recommends patients eligible for palliative care include those of any age (neonates, children, adolescents, or adults)¹ who live with medical conditions that impact their quality of life such as:

- Chronic life-threatening or life-limiting injuries from accidents or other forms of trauma (e.g., traumatic brain or spinal cord injury, intracerebral and epidural bleeding of the brain, paralysis of one or more limbs).
- Congenital injuries or life-threatening conditions leading to dependence on life-sustaining treatments and/or long-term care, requiring the support of others to perform their activities of daily living (e.g., congenital brain injury, cerebral palsy, spina bifida, and congenital heart disease).
- Developmental and intellectual disabilities with concurrent serious or life-threatening illness (e.g., autism spectrum disorders, Down syndrome, Fragile X syndrome who concurrently are diagnosed with a serious or life-threatening illness or condition).
- Acute, serious, and life-threatening illness (e.g., severe trauma, acute stroke, and leukemia), where cure or improvement is a realistic goal, but the conditions themselves and/or their treatments pose significant burdens and may negatively impact quality of life.
- Progressive chronic or life-threatening conditions (e.g., peripheral vascular disease, malignancies, renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, conditions leading to significant frailty, neurodegenerative disorders, and the later stages of dementia).
- Serious illness and terminal illness (e.g., people living with end-stage dementia, terminal cancer, or severe disabling stroke) when recovery or stabilization is unlikely and for whom intensive palliative care is the predominant focus and care goal for the remainder of their lives.²

The need for palliative care is not limited to these conditions. The examples listed are illustrative only and are provided to serve as an example of possible diagnoses for medical situations in the above listed bulleted areas. These examples are not intended to be an exhaustive list, are not determinative, and are not definitive.

Palliative care should be available to any individual in any of the above eligibility categories, regardless of care setting, employment status, or financial status. Consideration for palliative care screening is recommended at the earliest opportunity, such as immediately after a patient is diagnosed with a serious illness or condition, or a terminal illness.

Based on a person's social or living situation or based on the availability of caregivers, palliative care might be needed sooner, or for other conditions, in order to best address an individual's situation. Diverse populations may also have medical or social needs that warrant palliative care consideration sooner to address culturally appropriate approaches. In addition, palliative care screening strategies must consider the individual's racial, ethnic, and other diverse backgrounds to ensure their care needs are competently identified and respectfully met.

Palliative care provides an extra layer of support not only to the individual living with any of the above medical conditions, but also includes the supportive needs of their caregivers and family members. The intensity, frequency, and range of medical and supportive services provided will depend on the need of the individuals (*both patient and their caregivers*) and will vary over the course of an individual's illness or condition.

¹ National Consensus Project. (2013). Clinical Practice Guidelines for Quality Palliative Care, Third Edition. *National Consensus Project for Quality Palliative Care*. Pg 8-9.

² *Ibid.*

Palliative Care Settings

Palliative care is appropriate in any care setting where the patient lives. Settings include a variety of settings including but not limited to:¹

- Public facilities
- Private facilities
- Private homes
- Veterans' hospitals
- Outpatient clinics
- Skilled or intermediate care facilities
- Transitional care facilities
- Assisted living facilities
- Memory care facilities
- Group homes
- Rehabilitation centers
- Long-term care hospitals
- Hospice residences
- Correctional facilities
- Homeless shelters

The preceding bulleted list provides examples of where a patient may live. Patients may also receive palliative care in an inpatient hospital setting while they are receiving, or recovering from, medical treatments. Upon discharge from the inpatient setting, the patient may return to their original care setting, or they may transition to a new care setting. While the patient is living with a serious illness or condition, or is terminally ill, palliative care is vital, providing critical support to both the patient and their caregivers wherever the patient lives.

While the care settings above outline places where a patient lives, **payers frequently make a distinction between a patient who is home-bound versus home-based.**

Home-bound is defined where the patient lives, but is unable to leave their house

Home-based is defined where the patient lives but is able to physically leave their house.

Home-bound patients are typically eligible to receive coverage for palliative care in the home, while patients who are home-based are not.

The Council supports the patient's eligibility to receive coverage for palliative care regardless of care-setting and regardless of whether the patient is home-bound or home-based.

Palliative Care Medical and Supportive Needs

Both medical needs and supportive needs must be considered when a patient is diagnosed with a serious illness, or life-limiting or life-threatening condition.

Medical needs are those medical and surgical interventions used to treat the patient's illness or condition. Treatments may be invasive and complicated. They might temporarily, or even permanently, reduce the patient's ability to perform essential *self-care – Activities of Daily Living (ADLs)* or *interact effectively with their environment, known as Instrumental Activities of Daily Living (IADLs)*.

Supportive needs refer to the help necessary to support the patient's ADLs and IADLs. Family members frequently become caregivers and provide this support. *Supportive needs also include supporting the caregiver and the family so they in turn can provide the best possible care for the patient.*

Self-care, also referred to as Activities of Daily Living (ADLs), is the patient's ability to take care of their personal needs. ADL examples include:²

- Dressing
- Feeding
- Bathing/showering
- Personal hygiene
- Toileting

Interacting with their environment, also referred to as *Instrumental Activities of Daily Living (IADLs)*, includes those responsibilities the patient has regarding care for the physical, emotional, mental, spiritual, and financial health of their household. *IADL examples include:*³

- Care of others
- Care of pets
- Child rearing
- Communication management
- Driving and community mobility
- Financial management
- Health management and maintenance
- Home establishment and maintenance
- Meal preparation and clean up
- Religious and spiritual activities and expressions
- Safety procedure and emergency responses
- Shopping

The ADLs and IADLs listed are oriented toward the adult patient. Pediatric patients (0-17 years old) may also be diagnosed with serious illnesses or life-limiting / life-threatening conditions. Caregivers for pediatric patients are faced not only with the child's medical needs – *but also face the additional challenges of meeting the child's developmental needs as the child ages.*

Pediatric patients range in age from in utero to age 20. Developmental stages include:⁴

- In utero (before birth)
- Newborn (at birth)
- Infant (0-1 years)
- Toddler (2-3 years)

- Preschoolers (4-5 years)
- Middle Childhood (6-11 years)
- Young Teens (12-14 years)
- Teenagers (15-17 years)
- Young adults (18-20 years)

Developmental needs are skills that may be learned or evolve as the child grows: or in some health care situations, decline. Development needs⁵ can include:

- Gross motor skills
- Fine motor skills
- Speech / Language
- Cognitive / Problem Solving
- Social and Emotional

Unfortunately, for pediatric patients, usual developmental milestones may be delayed, never achieved, or lost through the trajectory of the pediatric patient’s illness or condition.

According to the Center to Advance Palliative Care (CAPC), the need for Pediatric Palliative Care is increasing:

- Children with medical complexity are increasing in prevalence because of increased survival rates of infants born prematurely, with congenital anomalies, and/or with chronic conditions, as well as improved treatments for acute illness in fields such as intensive care and oncology.⁶
- Prevalence estimates of the US children currently living with life threatening or chronic, complex conditions such as congenital and chromosomal abnormalities, diseases of the nervous system, or cancer, range from 400,000 and up; and more than 40,000 infants and children die annually.⁷
- As many as 17 million adults are serving as caregivers to a seriously ill child.⁸

In addition to assisting either pediatric or adult patients with their ADLs and IADLs, family caregivers may need to perform complex medical and therapeutic tasks as an extension of health care systems. They also may be tasked to ensure the patient adheres to the prescribed therapeutic regimens.

Since the 1980s, hospital inpatient stays for both pediatric and adult patients have shortened, **shifting more care into the home and community. As a result, individuals with serious illness are becoming more dependent on family caregivers to address gaps in care.** Increasingly, these caregivers must understand the care recipient’s condition and acquire new skills to execute complex medical/nursing tasks, previously performed by skilled providers in institutional settings.⁹

Examples of medical and therapeutic tasks that caregivers may perform include:

- Managing medication
- Intermittent bladder catheterization
- Changing ostomy (stool) bags
- Assisting with home dialysis
- Assisting with physical therapy
- Procuring and overseeing the use of medical equipment
- Enteral nutrition through a feeding tube or IV hydration or nutrition.

For patients and caregivers, palliative care is essential. Palliative care focuses on the whole person – physical, spiritual, psychosocial, and emotional, easing the patient’s pain and discomfort, reducing stress for the patient as well as their caregivers. Caregiving is hard work – *because of this, family caregivers may experience their own* Palliative Care 2023 Annual Legislative Report

*physical, mental, and financial health decline because of their caregiving experience.*¹⁰ The goal of palliative care is to help patients and their caregivers have the highest quality of life possible. It is that ‘extra layer of support’ – *treating the symptoms of the patient’s illness and providing support for the entire family.*¹¹

Examples of palliative care services include:

- Pain and symptom management, e.g., anxiety, shortness of breath, fatigue, and other challenges that are the results of a chronic or serious condition and the treatments for that condition.¹²
- Education regarding diagnosis and treatment options
- Care coordination with the patient’s current physicians and entire healthcare team, including the patient’s caregivers or health care agent(s)
- Coordination with the county services and schools
- Assistance with the development of the patient’s personal plan of care
- Practical help with the completion of insurance forms and making decisions about options for the patient’s care and/or housing
- Referrals to appropriate community resources for services
- Help with defining and documenting the patient’s advance directives and POLST’s
- Spiritual care, if desired¹³
- Emotional and psychosocial support for the patient and family as they face multiple challenges

Palliative care is designed to support more than just the patient – it provides emotional support to the patient, and the whole family – *family, as defined by that patient. The patient’s caregivers typically come from this family, whether they are close relatives, or extended relatives or even part of a family that exists because of community.*

Palliative care is triggered based on the patient’s serious illness or life-limiting / life-threatening diagnosis. While caregiving for the patient, caregivers may develop health problems and become patients themselves, further challenging their ability to provide needed care to others.

Although aspects of family caregiving can be rewarding, the role also has a substantial impact on the physical, mental, social, spiritual, and financial health of the caregiver. Importantly, the health effects of caregiving may be amplified in serious illness due to requirements for more caregiving hours, greater likelihood of performing complex medical/nursing tasks, and for many, involvement in the complex decision making associated with life-limiting illness.¹⁴

Compared with their counterparts not engaged in the role, caregivers report less optimal physical and mental health status; higher levels of depression, stress, distress, and burden; and higher levels of spiritual distress.¹⁵

In the *2020 Caregiving in the U.S.* report sponsored by AARP and the National Alliance for Caregiving, caregivers report physical, emotional, and financial strain, with 2 in 10 reporting they feel alone (21 percent). Caregivers reporting their own health as excellent or very good is down from 48 percent in 2015 to 41 percent in 2020.¹⁶

Additionally, concerning statistics regarding caregivers include:

- 1 in 4 caregivers find it difficult to take care of their own health.
- 23% report caregiving has made their own health worse.¹⁷
- 1 in 5 employees are caring for an adult or someone in their family who has an illness:
 - 20% report having to quit their job
 - 40% report they went to part-time work

- Employed caregivers experienced additional emotional stress when considering promotions, extra work, or changing jobs.
- While some employers support caregivers, not all caregiving support is available in the community where the employee lives.

The COVID-19 pandemic has challenged caregivers' ability to care for their own mental health. A recent report based on a nationwide survey from the Centers for Disease Control and Prevention (CDC) about the types of mental health challenges people faced during the pandemic found that **nearly 31% of unpaid family caregivers reported seriously considering suicide in the preceding 30 days compared with the 11% of the other adults taking the survey who were not caregivers** [survey was administered by the CDC from June 24 to June 30, 2022, and included almost 5,500 adults].¹⁸

Seventy-two percent of people who say they feel alone as an unpaid family caregiver say they also have high emotional stress, according to the study.¹⁹

Early availability of palliative care after the new diagnosis of a serious illness or condition is crucial for both patient and their caregivers, as it helps provide relevant medical education and assistance in navigating unfamiliar situations.

Because caregivers operate as home-based “care coordinators” and personal advocates for the patients,²⁰ caregivers are well-positioned to provide relevant and timely feedback to medical professionals regarding the patient’s pain level, state of mind and ability to perform ADLs and IADLs. As such, the family caregiver is, or should be, considered an important part of the medical interdisciplinary team (IDT).

¹ Adapted from National Consensus Project for Quality Palliative Care. (2018). Clinical Practice Guidelines for Quality Palliative Care, 4th edition. *National Coalition for Hospice and Palliative Care*. Retrieved from <https://www.nationalcoalitionhpc.org/ncp/> pg 5

² Adapted from verywellhealth. What to Know About ADLs and IADLs: Essential Tasks Needed to Sustain Survival and Well-Being. Retrieved August 1, 2022 <https://www.verywellhealth.com/what-are-adls-and-iadls-2510011>

³ *Ibid.*

⁴ Child Development / Positive Parenting Tips. *Center for Disease Control and Prevention*. Retrieved August 1, 2022 <https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/toddlers.html>

⁵ The Division of Developmental Pediatrics. Snapshots Developmental Milestones. Department of Pediatrics, Faculty of Medicine and Dentistry, University of Alberta. Retrieved August 31, 2022 [The Division of Developmental Pediatrics](https://www.ualberta.ca/division-of-developmental-pediatrics/).

⁶ Cohen E, Kuo DZ, Agrawal R, et al. (2011 March, Vol 127, Issue 3). Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/21339266/>

⁷ J Xu, SL Murphy, KD Kochanek, and BA Bastian. (2016 February 16). Deaths: Final Data for 2013 (64) 2 (February 16, 2016). *National Vital Statistics Reports*, CDC. Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf

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⁹ Bell, Whitney, and Young. (2019). Family Caregiving in Serious Illness in the United States: Recommendations to Support an Invisible Workforce. *Journal of the American Geriatrics Society*. Volume 67, Issue S2. Retrieved from <https://doi.org/10.1111/jgs.15820>

¹⁰ Olsen, Jennifer. (2021 November 8). Moderator. Minnesota Serious Illness Action Network: Fall Forum on Caregiving, Virtual.

¹¹ Adapted from CaringInfo: What is Palliative Care. Retrieved August 31, 2022 <https://www.caringinfo.org/types-of-care/palliative-care/>

¹² [Palliative Care - Minnesota Department of Health \(state.mn.us\)](https://www.health.state.mn.us/diversity/palliative-care/)

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- ¹³ Adapted from CaringInfo: What is Palliative Care. Retrieved August 31, 2022 <https://www.caringinfo.org/types-of-care/palliative-care/>
- ¹⁴ Bell, Whitney, and Young. (2019). Family Caregiving in Serious Illness in the United States: Recommendations to Support an Invisible Workforce. *Journal of the American Geriatrics Society*. Volume 67, Issue S2. Retrieved from <https://doi.org/10.1111/jgs.15820>
- ¹⁵ *Ibid.*
- ¹⁶ National Alliance for Caregiving. (2020 May.) Executive Summary: Caregiving in the U.S. AARP and National Alliance for Caregiving. AARP Research Report. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2020/05/executive-summary-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.003.pdf> pg ES-3
- ¹⁷ *Ibid.*
- ¹⁸ Weinstock, Cheryl. (2020, August 24). Unpaid Family Caregivers Have Heightened Thoughts of Suicide. *AARP*. Retrieved from <https://www.aarp.org/caregiving/health/info-2020/coronavirus-increased-suicidal-ideations.html>
- ¹⁹ *Ibid.*
- ²⁰ American Psychological Association. Retrieved October 1, 2022 <https://www.apa.org/pi/about/publications/caregivers/faq/family>

Palliative Care Health Care Interdisciplinary Team (IDT)

A health care **interdisciplinary team** (IDT) team is defined as a collaboration of medical professionals with different specialties working together to address the range of patient needs during a medical episode. There are different types of IDTs within the medical setting, with each type of IDT focusing on a different aspect of medical care.

While there are several types of interdisciplinary teams within medical settings, the palliative care IDT focuses on supporting the whole patient and the whole family. The previous section, *Medical and Supportive Needs*, identified a range of services patients and their caregivers may need as they navigate the trajectory of complex illnesses and conditions.

To address and assess patient and caregiver needs, the **core roles** of the palliative care IDT must include:

- Physicians, Physician Assistants, or Advanced Practice Registered Nurses (APRN)
- Nurses
- Social workers
- Spiritual counselors
- Caregiver and/or health care agent¹
- Child life specialists for pediatric patients.

Additional IDT members / roles may be added to the IDT based on the complexity of the patient's medical or patient and family caregiver supportive needs. These additional roles include, but are not limited to:

- Dietitians
- Therapists
- Pharmacists
- Chiropractors
- Acupuncture
- Complementary or alternative health care practices. A partial list of identified practices is shown below. *Please refer to MN Statute 146.01 for the full defined list identified in this statute.*²
 - Acupressure
 - Aromatherapy
 - Ayurveda
 - Culturally traditional healing practices
 - Traditional Oriental practices, such as Qi Gong
 - Healing Touch
 - Music therapy
 - Massage therapy

- Mind-body healing practices
- Meditation

*Note: A distinction is made between the **medical professional** – implies one person – and the **role** where one person may function in two roles. For example, a person may be certified or licensed as a social worker **and** a spiritual counselor – in this case allowing one person to fill both the social worker and spiritual counselor roles on the palliative care IDT.*

This same role distinction applies to the roles of caregiver and health care agent. A health care agent is defined as the patient’s legally authorized surrogate medical decision-maker. In some instances, one person may function both as the patient’s caregiver AND health care agent; in other instances the patient may have designated a health care agent that is not part of the family caregiving team.

The role of the palliative care IDT is to provide that extra layer of support to not only the patient, their family and caregivers, but to the treating medical team. Through assessments and observations, the palliative care IDT determines what supports would be beneficial to the patient, caregivers, and family members.

The next section outlines potential payment and reimbursement models supporting the work of the core and expanded IDT.

¹ Adapted from Friedman and Tong. 2020. A Framework for Integrating Family Caregivers Into the Health Care Team. *Rand Corporation*. Retrieved from <https://doi.org/10.7249/RR105-1>

² Adapted from [Sec. 146A.01 MN Statutes](#). Minnesota Legislature. Retrieved October 1, 2022 <https://www.revisor.mn.gov/statutes/cite/146A.01>

Palliative Care Tiered Services

The moment a patient is diagnosed with a serious illness or life-limiting or life-threatening condition, a referral for a palliative care screening consultation is appropriate and provides the most benefit for the patient and their caregivers. In one study of cancer patients, early palliative care engagement was proven to reduce hospital inpatient care and emergency department visits by 15% and 20% respectively.¹

Patients are living longer with serious illness, and their care is moving out of the hospital and into community care settings. For the sickest patient, this means care delivered in the home.²

Patients may need palliative care in a community setting if they:³

- Do not meet criteria for hospital admission, yet need support
- Do not meet criteria for either home health care or hospice
- Are frail and want to stay out of the hospital
- Have a child with a serious illness and chronic care needs that negatively impacts quality of life

Palliative care focuses on the whole patient and the whole family. The palliative care consultation considers:

- The patient's medical care needs
- The patient's supportive needs
- The family / caregivers' supportive needs

While the diagnosing physician focuses on the patient's medical needs and treatment plan, a palliative care consultation assesses the supportive needs of the patient and their caregiver(s).

During the initial palliative care consultation, the palliative care team evaluates the **patient's readiness and ability to successfully navigate their current medical status**. The initial palliative consultation also evaluates the **patient's supportive needs** and the **availability and ability of family caregivers to meet those supportive needs**.

The palliative care team also assesses the patient's ability – *along with their caregiver's ability* – to navigate the patient's medical status and treatments based on factors including but not limited to:

- **Understanding of their disease(s)**
 - Does the patient and their family caregivers understand the patient's current diagnosis, prognosis, medical treatment plan, and disease trajectory?
 - Does the patient and/or their family need disease / condition specific medical education?
 - Are there multiple specialty providers treating the same patient, e.g., a cardiologist, a pulmonologist, and an oncologist?
- **Able to articulate their (the patient's) goals of care**
 - Is the patient able to make **an informed decision regarding the medical treatment plan versus just giving informed consent** for a specific medical procedure or treatment?

- **Informed decision** implies a decision that balances treatment options with patient preferences articulated and is articulated in their goals of care.
- **Informed consent** gives permission for the treating medical team to proceed with a specific medical procedure or treatment, e.g., surgery, or chemotherapy.
 - Are the treatment options aligned with the patient’s choices, such as no treatment, wish to stay at home, pain management only?
 - **Does the medical team and/or family understand the patient’s goals of care?**
- **Availability and ability of caregivers.**
 - Does the patient have adequate family caregiving support given the patient’s diagnosis, prognosis, medical treatment plan, disease trajectory, and their goals of care?
 - Do caregivers live close enough to provide hands-on support? Do caregivers have enough time to meet the patient’s current and future supportive needs when the patient’s ability to perform their activities of daily living (ADLs) and Instruments of Activities of Daily Livings (IADLs) declines?
 - Do caregivers have the willingness to perform medical procedures, such as wound dressing, changing ostomy bags, assisting with bathing or toileting, or medication management?
- **Availability of advance care planning documents including but not limited to a health care directive or Provider Orders for Life-Sustaining Treatment (POLST).**
 - Does the patient have a health care directive / designated health care agent (surrogate) medical-decision maker when the patient cannot, or chooses not to, make their own medical decisions?
 - If yes, the patient has a health care directive, is it current, or does it need to be updated?
 - If no, does the patient need assistance to create one?
 - Has the patient discussed their health care directive with their health care agent?
 - Are other family members aware of – and supportive of – the patient’s health care directive?
 - Does the patient need a physician’s help creating / updating a Provider Orders for Life-Sustaining Treatment (POLST) to ensure the patient’s medical care choices are honored by Emergency Medical Teams (EMTs), Emergency Departments (ED) and understood by family caregivers / partners?

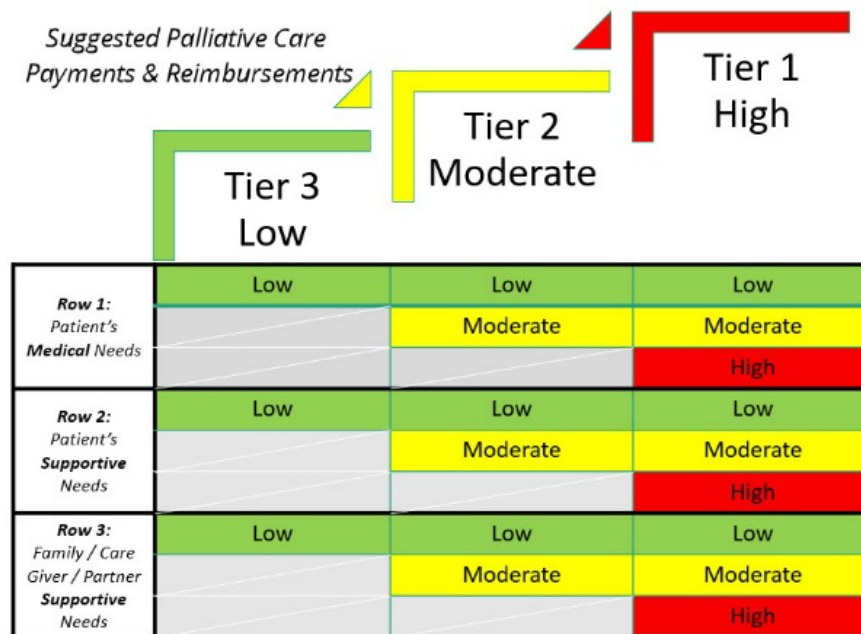
Palliative Care Consults

- **Initial consult.** First time consultation. Ideally a palliative care referral is made as part of the conversation regarding a serious illness / condition or terminal diagnosis. If the referral is not made immediately, it is preferred as early as possible to give the patient and their caregivers early and timely information.
- **Periodic review / re-assessment consultations.** Periodic review triggered either by set time intervals, (e.g., every 3 months) or by change in patient’s medical condition (improving, declining, or done), or changes to caregivers’ availability or needs.
- **Status change review.** Review triggered by change in status, e.g., either the patient needs more medical or supportive care and/or the caregivers need more supportive care; either the patient needs less medical or supportive care and/or the caregivers need less supportive care.

- **Payment model to consider.** Fee for service, episodic payments (allowing time for patient completion on disease education, goals of care, and health care directive).

Payment Tiers

Suggested payments tiers consider the **patient’s medical needs**, the **patient’s supportive needs**, and the **family/caregiver supportive needs**, assigning each a classification of low, moderate, or high based on the level of need identified during the palliative care consult. The combination of the patient and family/caregiver needs allows for palliative care payments and reimbursements to be variable, matched to, and changing with, the overall needs of both the patient and their caregivers.



As shown in the graphic, **needs classifications are reflected in each row** as either Low (green), Moderate (yellow) and High (red). Row 1 indicates a patient’s medical needs. Row 2 indicates a patient’s supportive needs. Row 3 indicates family/caregiver supportive needs.

The suggested payment and reimbursement tier is based on the column.

- If **all** rows are Low (green) the resulting payment is **Tier 3 / Low**.
- If **any of the three rows** contain a **combination of green or yellow (but no red)**, the payment tier reflects the Tier 2 / Moderate.
- If any row contains red, then the payment tier is Tier 3 / High.

Each payment and reimbursement tier is explored below. Referring to the graphic, the payment tier is tied to the highest need.

Tier 3 [lowest level of support]:

- **Low medical or supportive needs.** Patient requires low medical care, and patient/family/care partners have low supportive care needs.

- **Timely palliative care consults.** Initial consult, then palliative care re-assessment every 6 months or triggered by changes in patient’s medical condition, improving, declining, or medical treatments completed, or changes to caregivers’ availability or needs.
- **Payment model to consider:** episodic payments at specified time interval, 30-45-60 days; monthly bundled / per member per month; low tiered bundled payment

Tier 2 [moderate level of support]:

- **Moderate medical or supportive needs.** The patient has low or moderate patient medical needs, and the patient or the family caregivers / partners have low or moderate supportive care needs. *If either the patient / family / caregivers have any moderate needs, then medical / supportive care is provided at the moderate or tier 2 level.*
- **Timely palliative care consults.** Initial consult, then palliative care re-assessment every 6 months or triggered by changes in patient’s medical condition, improving, declining, or medical treatments completed, or changes to caregivers’ availability or needs.
- **Payment model to consider:** episodic payments at specified time interval, 30-45-60 days; monthly bundled / per member per month; middle tiered bundled payment.

Tier 1 [high level of support]:

- **High medical or supportive needs.** The patient has low, moderate, or high patient medical needs, and the patient or the family caregivers / partners have low, moderate, or high supportive care needs. *If either the patient / family / caregivers have any high needs, then medical / supportive care is provided at the high or tier 1 level.*
- **Timely palliative care consults.** Initial consult, then palliative care re-assessment every 6 months or triggered by changes in patient’s medical condition, improving, declining, or medical treatments completed, or changes to caregivers’ availability or needs.
- **Payment model to consider:** monthly bundled / per member per month; high tiered bundled payment.

This discussion on Tiered Services leads into the following section on Palliative Care Payments and Reimbursements.

¹ Dembeck, Lauren PhD. (2021, June 8). Early Palliative Care Reduces End-of-life Health Care Costs. *OncologyNurseAdvisor*. Retrieved from <https://www.oncologynurseadvisor.com/home/headlines/conference-coverage/asco-2021/cancer-early-palliative-care-reduces-end-life-healthcare-cost-treatment/>

² Center to Advance Palliative Care. *Designing a Home-Based Palliative Care Program*. Retrieved November 4, 2022 <https://www.capc.org/toolkits/designing-a-home-based-palliative-care-program/>

³ Adapted from Center to Advance Palliative Care. *Palliative Care in the Community*. Retrieved November 4, 2022 <https://www.capc.org/palliative-care-community/>

Palliative Care Payments / Reimbursements

Recommended Action #3: Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.

UPDATE: In progress. The recommended Palliative Care Core Services outlined in the prior section is the foundation for this section on payments and reimbursements. This section will also be discussed with Stakeholders during 2023 and updated based on their feedback.

Treating physicians spend the majority of their time focused on the patient’s medical needs and how the patient is responding to prescribed treatment(s).

An increased focus on **patient-centered** care encourages patients’ involvement in their own care, and [should] include family members in decision-making, yielding a more **family-centered care** focus.¹

Given the current payment and reimbursement models, **there is little paid time available for treating physicians to have conversations about, or with, the patient and the patient’s caregivers regarding their individual and collective supportive needs.**

It takes time to have a patient-centered/family-centered focus and conversations. Time a medical provider may not have or be paid for – *“You get this sinking feeling when you’re having a busy day and you walk into a patient’s room in the hospital and you see a bunch of family around and you’re worried it’s going to take [too much] time.”²*

Whether inpatient (hospital) or community-based palliative care, the palliative care IDT is designed to provide that extra layer of support for the treating physician(s) by shifting time-intensive conversations to a palliative care IDT. **This enables treating physicians to focus on the patient’s medical treatments while also ensuring patient and caregiver supportive needs are understood.**

As noted earlier in this report, inpatient hospital stays for both pediatric and adults have shortened, **shifting more care into the home and community, leaving individuals with serious illness reliant on family caregivers to address gaps in care.** Increasingly, these caregivers must understand the care recipient’s condition and acquire new skills to execute complex medical/nursing tasks, previously performed by skilled providers in institutional settings.³

Caregivers frequently learn those new complex medical/nursing skills and tasks “on the job,” meaning the caregiver is learning how to perform the task while caring for the patient.

Why is focusing on the caregiver so important? When a patient’s medical status is declining, caregivers make crucial decisions on behalf of the patient.

Decisions made by caregivers include, but are not limited to:

- **When to call** a medical provider, e.g., what symptoms are normal; when does normal become concerning versus urgent, versus life-threatening?

- **Who to call**, e.g., primary care physician, specialty care physician, or which specialty care physician if more than one is treating the patient (e.g., an oncologist, cardiologist, pulmonologist)?
- **Where to take the patient** if they are not able to reach the patient’s provider, e.g., physician’s clinic, urgent care, emergency care?
- **How to transport the patient**, e.g., safe to self-transport or need to call an ambulance?

Caregivers are also often referred to as “invisible patients”: their health, well-being, emotional, social, financial, spiritual, and physical ability to care for patients (their loved ones) can influence patient outcomes. It also contributes to a cycle of morbidity and mortality, with caregivers dying at higher rates than non-caregivers.⁴

Caregivers frequently choose between getting care for themselves with their own medical diagnosis or ensuring that their loved one, the patient, is cared for during the disease condition trajectory. Caregivers may miss their own screenings -- resulting in treatable illnesses / disease being caught later with potentially more complex medical treatments and/or a lower success rate, given delays in getting treatment.

Merging the complexity of the patient’s serious illness or condition, the medical needs of the patient, and the supportive needs of the patient and their family or care partner suggests a complexity of care needs that may be misleadingly simplified by a tiered structure of palliative care services and reimbursements.

Not all patients will need palliative care and the support that palliative care provides. Neither will all caregivers need their own additional support as they navigate the patient’s disease trajectory. In addition, the need for palliative care fluctuates over time. Some patients will need more support while their caregivers may not; some patients may not need any palliative care support as their caregivers are providing the support they need – however those caregivers may be feeling the burden of caregiving in ways that the patient may not understand and that need significant support.

Navigating the challenges of who needs what support and when will be unique to each combination of patient and supporting caregivers. Just as the patient may improve or decline, or treatment comes to an end, patient / caregiver supportive needs will also change over time and should be periodically re-assessed during the course of treating the patient.

As suggested during the Palliative Care Advisory Council’s 2022 Legislative Annual Report, tiered services as a benefit structure makes sense allowing the patient to receive what is needed – and wanted – while avoiding aggressive care that may not be wanted or appropriate.

Initial or Recurring Palliative Care Assessment Consultation

- **Initial consult.** First consultation with palliative care team after diagnosis of a serious illness.
- **Scheduled review / re-assessment consultations.** Periodic review triggered either by set time intervals, (e.g., every 3 months); or by change in patient’s medical condition, improving, declining, or done; or changes to caregivers’ availability or needs.
- **Status change review.** Review triggered by change in status, e.g., patient needs more medical or supportive care and/or caregivers need more supportive care; patient needs less medical or supportive care and/or caregivers need less supportive care.

- **Payment model to consider:** fee for service, episodic payments (allowing time for patient completion on disease education, goals of care, and health care directive)

Tier 3: (Lowest level of support defined)

- Patient had three or fewer comorbidities prior to the serious illness or life-limiting / life-threatening diagnosis
- Patient's pain and symptoms are controlled
- Patient is able to perform the majority of ADLs / IADLs
- Caregiver is able to provide support to the patient for any ADLs / IADLs
- Caregiver is able to perform any medical or therapeutic tasks
- Patient and/or caregiver, are able to navigate the medical system
- Patient and/or caregiver are able to navigate the referrals, insurance, and financial aspects of care and/or housing
- Patient and/or caregiver do not have any emotional or psychosocial unmet needs
- Patient does not need help with health care directive

Tier 2: (Moderate level of support defined)

- Patient had three (3) to seven (7) comorbidities and/or the presence of one (1) or more serious illnesses or conditions
- Patient's pain and symptoms are usually controlled, however break-through pain is occurring
- One (1) hospital admission or one (1) or more trips to the ER within the last 6 months
- Patient is not able to perform the majority of ADLs / IADLs without assistance
- Caregiver may or may not be able to provide support to the patient for any ADLs / IADLs
- Caregiver may or may not be able to perform any medical or therapeutic tasks
- Patient and/or caregiver may need help navigating the medical system
- Patient and/or caregiver may need help navigating the referrals, insurance, and financial aspects of care and/or housing
- Patient and/or caregiver may have emotional or psychosocial unmet needs
- Caregiver has begun to delay their own wellness care or medical care for existing illnesses or conditions due to caregiving for the patient
- Patient may need help with health care directive

Tier 1: (Highest level of support defined)

- Patient had seven (7) or more comorbidities and/or the presence of one (1) or more serious illnesses or conditions

- Patient’s pain and symptoms may not be controlled, with break-through pain occurring frequently
- More than one (1) hospital admission or readmission, or two (2) or more trips to the ER within the last six months
- Patient is not able to perform the majority of ADLs / IADLs without assistance
- Caregiver may or may not be able to provide support to the patient for any ADLs / IADLs
- Caregiver may or may not be able to perform any medical or therapeutic tasks
- Patient and/or caregiver may need help navigating the medical system
- Patient and/or caregiver may need help navigating the referrals, insurance, and financial aspects of care and/or housing
- Patient and/or caregiver may have emotional or psychosocial unmet needs
- Caregiver has begun to delay their own wellness care or medical care for existing illnesses or conditions due to caregiving for the patient
- Patient may need help with health care directive

The goal is to provide standardized palliative care consistently throughout the patient’s disease or condition trajectory as well as across care settings (including inpatient, outpatient, community, and long-term care), from the earliest moment after diagnosis to end-of-life, and through the bereavement period of the family and caregivers.

It is the goal of the Council to recommend, consistent with the definition it has proposed to the Legislature, a defined set of palliative care services before the next legislative session, laying the foundation to work with payers regarding the development of a consistent, standardized payment model for a defined set of palliative care services.

¹ Friedman and Tong. 2020. A Framework for Integrating Family Caregivers Into the Health Care Team. *Rand Corporation*. Retrieved from <https://doi.org/10.7249/RR105-1>, pg 3

² *Ibid*, pg 8

³ Bell, J., Whitney, R., and Young, H. (2019) Family Caregiving in Serious Illness in the United States: Recommendations to Support an Invisible Workforce. *Journal of the American Geriatrics Society*. Volume #67 (Issue S2). <https://doi.org/10.1111/jgs.15820>

⁴ Center to Advance Palliative Care. 2022. Supporting the Family Caregiver: Key Takeaways for Care Managers. Retrieved from <https://www.capc.org/documents/download/945/>

Palliative Care Comparative Cost Study

Recommended Action #4: Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

[NEW] Recommended Action #5: Apply for a Medicaid 1115 Waiver by 12/31/2024.

[NEW] Recommended Action #6: Require data collection to support the Medicaid 1115 Waiver include data that identifies Minnesota’s health disparities.

UPDATE: In progress. The recommended Palliative Comparative Cost Study uses the information presented in this report to identify individuals eligible for palliative care and those potential services these individuals receive while eligible for palliative care. This section will also be discussed with Stakeholders during 2023 and updated based on their feedback.

“Palliative care improves quality of life and reduces symptom burden. Palliative care provides the care that patients want – and because it meets their needs, it reduces unnecessary utilization of crisis care. Its focus on the highest-need and highest-cost patient segment, accounting for the majority of spending, makes it an essential strategy for population health management.”¹

The statement above, as noted in the Council’s 2022 Annual Legislative Report, acknowledges the value of palliative care. The Council, however, recognizes there are few, if any, Minnesota-specific palliative care financial benefit studies available.

While financial impacts are identified at the federal level, and through several states, the Council recognizes that a comparative cost study should be conducted on Minnesota patients using the newly recommended criteria for palliative care eligibility and tiered payments.

The Council acknowledges the lack of current and Minnesota specific palliative care data that could be used to identify and address health disparities. Health disparities is experienced by differences in access to and care received by gender, race or ethnicity, education, income, disability, geographic location and sexual orientation among others. Social determinants of health like poverty, unequal access to health care, lack of education, stigma, and racism are also linked to health disparities.² Collection of this data should be incorporated into the comparative cost study.

While the Council examined the best way to conduct such a cost study, the Council did not pursue funding during the 2022 legislative cycle and therefore has not begun a comparative cost study at this time. The Council did, however, explore options of what a comparative cost study might include, e.g., a “demonstration” project or a “denominator” project.

A **demonstration project** according to Medicare’s definition, studies the likely impact of new methods of service delivery, coverage of new types of service, and new payment approaches on beneficiaries, providers, health plans, and states.³ Demonstration projects take time and are costly to conduct.

Exploring a demonstration project conducted by Coalition for Compassionate Care of California (CCCC) and California Health Care Foundation (CHCF), the project used criteria to identify patients eligible for, but not using palliative care, patients / family caregivers enrolled in palliative care – and then *compared the plan expenses for the same amount of time before and after palliative care enrollment*.⁴

The CCCC and CHCF demonstration project reported the following results:⁵

- 25% - 31% cost reduction for all insurance types combined when comparing 120 days pre and 120 days post
- 42% - 51% cost reduction for Medicaid comparing 120 days pre and 120 days post
- 24% - 30% cost reduction for commercial insurers when comparing 120 days pre and 120 days post

A recent report from the National Academy for State Health Policy (NASHP) provides data-driven results using an actuarial analysis of palliative care for state Medicaid programs. Findings of the analysis included⁶:

- Effective administration of a Medicaid palliative care benefit for the **highest service utilizers could produce cost avoidance savings ranging between \$231 and \$1,165 per Medicaid member per month**, with potential return on investment ranging between \$0.80 and \$2.60 for every \$1 spent on palliative care.
- Medicaid members with disabilities and those receiving long-term services and supports (LTSS) have a higher prevalence of serious illness.
- Medicaid members with serious illness use increasingly high levels of costly inpatient and emergency department services as they approach end-of-life.

A **denominator project** is more generic and more of a forecasting tool than a demonstration project. A denominator project would identify the percentage of Minnesota's population that is eligible for palliative care and then apply projected standard cost savings for that population, for example, the percentages reported for the CCCC and CHCF project above.

As is standard with forecasting, there is the **projected** increase/decrease and the **actual** increase/decrease. Should the eligibility criteria and the medical and supportive needs identified in an earlier section of this report be implemented, reporting could be created to identify the **projected** or **forecasted** savings for a period (pre) and followed by the **actuals** for the same reporting period.

If one accepts the cost avoidance savings identified by NASHP, then a denominator project using Minnesota's Medical Assistance (Minnesota's Medicaid) population, a lower cost denominator project could be used to extrapolate what Minnesota could expect for cost avoidance while increasing patient and family quality of life and satisfaction.

The Councils recommends that the Minnesota budget for 2023 include a line-item supporting a palliative care comparative cost study in the form of a denominator project.

¹ The Center to Advance Palliative Care. (n.d.) The Case for Community-Based Palliative Care: A New Paradigm for Improving the Care of Serious Illness. CAPC. Retrieved August 1, 2022 <https://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts>

² Center for Disease Control (CDC). 2023. Retrieved from <https://www.cdc.gov/nchhstp/healthdisparities/default.htm>

³ Centers for Medicare & Medicaid Services. CMS. Retrieved August 15, 2022 <https://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts>

⁴ Cassel, B., Kerr, K., & Thomas, J. (2022, February 2). *Community-Based Palliative Care: Lessons on Standardization and Scaling*. Affordability and Sustainability of Palliative Care Services across Medicaid, Medicare, and Commercial Insurance. Retrieved from <https://coalitionccc.org/common/Uploaded%20files/PDFs/Consensus%20Standards%20CBPC%202-2-22%20web.pdf> slides 27-29

⁵ *Ibid.*

⁶ National Academy of State Health Policy. NASHP. Retrieved December 13, 2022. <https://www.nashp.org/palliative-care-in-medicaid-costing-out-the-benefit-actuarial-analysis-of-medicaid-experience/#toggle-id-3>

Education, Training and Awareness

It is well established that patients with serious illness account disproportionately for health care utilization and costs.¹ It is estimated that fewer than 5% of patients who would benefit from palliative care services actually receive them.² This is both a consumer awareness issue and a workforce issue. The Education and Training Work Group recognizes that creating a robust palliative care workforce is crucial for attaining the Quadruple Aim. A healthcare system focused on patient-centered care, increased quality of care, reduced costs of care will also result in a more resilient workforce as the population continues to age. As a result, the Council's Education and Training work group has supported required palliative care education early in the training of all healthcare professionals.

This workgroup has researched and examined options and approaches to implementing required training. Mandated training through state licensing bodies was an early proposition. But the appetite for such requirements plummeted in the wake of the COVID-19 pandemic. Even though the pandemic highlighted how much our health system needs this kind of focused and patient-centered care, there is concern that this type of rudimentary and mandated education may create more frustration and drain our already tenuous healthcare workforce. Similarly, requirements at the employer level and payor level have many gaps and only place a Band-Aid on a gaping wound.

Therefore, the group genuinely feels that the best approach is to truly embed the appropriate education into the new learner's curriculum and create opportunities for ongoing learning for the current workforce. The workgroup also recognizes that most of this needed education already exists, so there is no need to reinvent the wheel. However, there is a growing need to consolidate it, make it easier to access and most importantly, fund it. This is where the Palliative Care and Hospice Education and Training Act (PCHETA) can create synergy with our goals. This bipartisan federal funding bill will "ensure an adequate, appropriately trained workforce is available to provide the pain and symptom management, intensive communication, and level of care coordination that addresses the episodic and long-term nature of serious and complex chronic illness."³

The American Academy of Hospice and Palliative Medicine has summarized the bill's key funding endeavors:⁴

PALLIATIVE CARE AND HOSPICE EDUCATION CENTERS

Establishes Palliative Care and Hospice Education Centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support the training and retraining of faculty; support continuing education; provide students with clinical training in appropriate sites of care; and provide traineeships for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies, with a focus in interprofessional team-based palliative care.

PHYSICIAN TRAINING

Authorizes grants or contracts to schools of medicine, teaching hospitals and graduate medical education programs to train physicians (including residents, trainees, and fellows) who plan to teach palliative medicine. Such programs will provide training in palliative medicine through a variety of service rotations, such as

consultation services, acute care services, extended care facilities, ambulatory care and comprehensive evaluation units, hospice, home health, and community care programs. Programs will be required to develop specific performance-based measures to evaluate the competency of trainees.

ACADEMIC CAREER AWARDS

Establishes a program to promote the career development of physicians who are board certified or board eligible in Hospice and Palliative Medicine and have a junior (non-tenured) faculty appointment at an accredited school of medicine. Eligible individuals must provide assurance of a full-time faculty appointment in a health professions institution and commit to spend a majority of their funded time teaching and developing skills in interdisciplinary education in palliative care.

WORKFORCE DEVELOPMENT

Establishes fellowship programs within the new Palliative Care and Hospice Education Centers to provide short-term intensive courses focused on palliative care. Supporting the team approach to palliative care, the fellowships will provide supplemental training for faculty members in medical schools and other health professions schools with programs in psychology, pharmacy, nursing, social work, physician assistant education, chaplaincy, or other allied health disciplines approved by the HHS Secretary so that providers who do not have formal training in palliative care can upgrade their knowledge and skills for the care of individuals with serious or life-threatening illness as well as enhance their interdisciplinary teaching skills.

CAREER INCENTIVE AWARDS

Provides grants or contracts for eligible health professionals who agree to teach or practice in the field of palliative care for at least 5 years. Eligible individuals include advanced practice nurses, social workers, physician assistants, pharmacists, or students of psychology who are pursuing a doctorate, master's or other advanced degree with a focus in palliative care or related fields in an accredited health professions school.

NURSE TRAINING

Creates special preferences in existing nurse education law for hospice and palliative nursing, in education, practice and quality grants, workforce development, and nurse retention projects.

PALLIATIVE CARE EDUCATION AND AWARENESS

Provides for the establishment of a national campaign to inform patients, families, and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness. Directs the dissemination of information, resources, and materials about palliative care services to health professionals and the public in a variety of formats, in consultation with professional and patient stakeholders.

ENHANCED RESEARCH

Directs the National Institutes of Health to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illness.

Without additional funding the palliative care and hospice provider workforce is estimated to grow just over one percent in the next 20 years while the number of patients eligible for palliative care will increase by more than 20 percent⁵. In addition to training specialty palliative care providers there needs to be an emphasis on primary palliative care skills. Every nurse, physician assistant (PA), physician, nurse practitioner (NP) and social worker should understand the basic principles of palliative care and be able to facilitate access to such care. Primary care physicians, PAs and NPs should have foundational knowledge of palliative care and be able to manage pain and symptoms and have patient-centered goals of care conversations. This is not unlike the fact that most high blood pressure or depression is managed by primary care providers. Specialty level care can then be provided by specialists when conditions are more complex. So, the emphasis on workforce development includes specialty and primary palliative care trained providers.

Because Minnesota is recognized as a national leader in the palliative care community, PCAC believes that Minnesota would be the perfect convener for a federally funded Palliative Care and Hospice Education Center. There is already informal discussion amongst the interested at the University of Minnesota, the Mayo Clinic, Minnesota Hospital Association, Minnesota Medical Association, Minnesota Network of Hospice & Palliative Care, the Serious Illness Action Network, Minnesota Association of Geriatrics Inspired Clinicians and Stratis Health just to name a few. There is also interest from the surrounding states. This collaboration would create an incubator and disseminator of palliative care knowledge in the upper Midwest. To this end Minnesota needs to develop a plan for application for such funding. This type of planning will require a great deal of coordination, a fiduciary agency and an investment by the state in support of application for this federal funding.

PCHETA has overwhelming bipartisan support federally and is expected to pass in the near future. Minnesota needs to be prepared to apply for funding and the creation of the Palliative Care and Hospice Education Center. This work needs to start now. Other states have created Palliative Care Advisory Councils or Task Forces. The work these groups have done is important but creating palliative care license plates or palliative care awareness months isn't enough. Now is the time to invest in the future of our healthcare system, the future of our healthcare workforce and the health of all Minnesotans regardless of age, race, gender identity, socioeconomic status, or health status. We cannot afford to look away. When PCHETA is passed, Minnesota needs to be ready for it.

Other recommendations for workforce development include:

1. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
2. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
3. Require medical schools to include minimum standards for primary palliative care education for all students.
4. Require physician residencies to include minimum standards for primary palliative care education for all residents.
5. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

¹ Sanborn, L., & Purington, K. (2019 May). *Palliative Care: A Primer for State Policymakers*. National Academy for State Health Policy. Retrieved from <https://nashp.org/wp-content/uploads/2019/05/Palliative-Care-A-Primer-for-State-Policymakers.pdf>

² Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q*. 2011;89(3):343-380.

³ American Academy of Hospice and Palliative Medicine. (n.d.) *Palliative Care and Hospice Education and Training Act*. Retrieved from http://aahpm.org/uploads/advocacy/PCHETA_Summary.pdf

⁴ National Hospice and Palliative Care Organization. (2022, May 19). Leading Hospice and Palliative Care Organizations Laud Introduction of PCHETA. Retrieved from <https://www.nhpco.org/leading-hospice-and-palliative-care-organizations-laud-introduction-of-pcheta/>

⁵ *Ibid.*

Diversity, Equity, and Inclusiveness (DEI)

The Palliative Care Advisory Council's statutory charge has been clear since its inception:

The Council's collective vision for palliative care is that all Minnesotans have access to high quality Palliative Care across populations, care settings, and geography.

Our health is determined to a large extent by the conditions of everyday life, and by the systems put in place to promote health, prevent disease, and to support the community during illness and injury. Healthcare professionals and healthcare systems need to be prepared to continue to address the unique needs faced by all Minnesotans, especially communities underserved by specialty healthcare, like Palliative Care. These needs are especially evident for racialized, Black, and Indigenous people, those at the lower end of the socioeconomic gradient, women, and gender-diverse people, people with disabilities, people living in under-resourced areas, and other equity-seeking communities. Evidence continues to point to how public policies and institutions create harm for individuals and communities based on race, religion, culture, and ethnic origin. Policies and institutional practices result in inequities in social inclusion, economic outcomes, personal health, and access to and quality of health and social services.

The Diversity, Equity, and Inclusion (DEI) Work Group recognizes that the Palliative Care Advisory Council cannot solve these deeply embedded issues within our systems, including healthcare; but we strive to identify, recognize, and support efforts which offer real solutions.

Guidance supporting diversity, equity, and inclusion activities and statements from other medical associations and organizations help to reinforce the work of the Council and have served as an additional source of information for our activities this year. We are mindful of the distinction between individual health care practitioners, whose roles are to treat and care, and the systems within which they work, which have caused harm to many within equity-seeking communities. In addressing systemic inequities, there must also be continued support for practitioners so they can work to heal our communities. The following tools offer guidance not only for professionals supported by these organizations, but also for the work needed to occur within our communities, state, and country.

American Academy of Neurology (excerpt)

"We cannot promote the best care for our patients or enhance the careers of our members if we ignore the pervasive inequities that are often insurmountable barriers to both. In the face of these historic and systemic issues, it is not enough to not be an anti-racist organization. We must speak out and lead in order to ensure change..."

National POLST (excerpt)

"...committed to promoting equality and improving the health and well-being of all persons living with serious illness or advanced frailty, their friends and loved ones, and the health care professionals caring for them, regardless of race, color, religion, national origin or citizenship status, geography, sex, gender identity or expression, sexual orientation, physical or mental disability, age or socioeconomic status."

Minnesota Network for Hospice and Palliative Care (MNHPC):

“We recognize that as members of the hospice and palliative care community, we have a responsibility for the existing historic, systemic, and institutional barriers to accessing high-quality serious illness and end-of-life care. We are committed to advancing equity and fostering a diverse and inclusive community, organization, and culture.”

National Hospice and Palliative Care Organization (NHPCO) (excerpt)

“...vision is a world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer. We demand that every life be valued and respected, and we believe in care without barriers. Everyone deserves compassion, comfort, peace and dignity during life’s most intimate and vulnerable experiences. This is not possible without eliminating the structural racism and health inequities that plague our health system and have resulted in racial minorities bearing a disproportionate burden of death and illness.”

We need only to survey the thoughtful work from colleagues to learn that change in our communities can be impacted by best practices. There has been a focus on greater awareness of providing opportunities for learning and improving care for our community. National organizations have also contributed to the education of our healthcare practitioners and leaders. The Center to Advance Palliative Care (CAPC) has developed education content (CME/CEU offered) to dismantle systemic racism in healthcare, and bias in healthcare. Including a letter to the editor to the Journal of Pain and Symptom Management (Authors Puja. J. Umaretiya, MD, et al.) outlining three pathways by which structural racism contributes to disparities in palliative care. These pathways include access to care, the patient-health care system interaction, and toxic stress. The authors suggest that these pathways could guide future interventions to dismantle disparities, to ultimately achieve equitable palliative care delivery. The Institute for Health Improvement (IHI) has developed content available for free to build skills for anti-racism work to counter structural racism and improve health equity (CME/CEU offered).

Dismantling systemic racism must occur through multiple levels, for all Minnesotans, and the impact will be appreciated by all who use healthcare. Some specific Minnesota examples are offered below for illustrative purposes.

Arts and Awareness

Twin Cities Public Television (TPT or PBS) has continued to produce and release important and timely documentaries and specials, this year namely the “Art + Medicine: Speaking of Race” has a number of publicly available sessions and content to support and further this community dialogue.

Blue Cross and Blue Shield has partnered with the Minneapolis Institute of Arts (Mia) to launch a multi-generational project that addresses racism and health through the power of art - using a collaborative approach to visualize the concept of racism as a health crisis.

Initiatives Within Minnesota Healthcare Organizations and Businesses

M Health Fairview, envisions through a multi-year strategic plan through the establishment of HOPE Commission which states, “Ultimately, the success of the Commission will depend on the active involvement of all 34,000 M
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Health Fairview employees — nurses, housekeeping staff, doctors, food service workers, care coordinators, administrators, and others — in advancing an equitable culture, practices, and outcomes.”

Utilization of data and metrics gathered by the state which then incorporates these data into business practice has been how Livio Health has developed opportunities to meet the needs of traditionally underserved communities. Livio Health started in 2015 as a mobile urgent care service, but has now expanded their service model, offering community based palliative care that is delivered to the client wherever they call home. With benchmark and use of public data, this company has set goals to enroll BIPOC people at 125% of benchmark. Essentially using the principal of parity and using person centered principles to meet the community where they live.

Minnesota Based Healthcare Education

The University of Minnesota Medical School has expanded many activities, specifically with the development of a writer’s workshop within the Center for the Art of Medicine (CFAM). This Center strives to cultivate creativity and to elevate the role of the arts and humanities in medical education and practice, in order to nurture curiosity and creativity, promote diversity, deepen empathy, develop professionalism, and foster resilience in physicians and physicians-in-training.

Another learning opportunity through the University of Minnesota, available to all and the general public is a free course called, “Honoring Choices Across Cultures: End of Life and Advance Care Planning.” The course is offered as part of a larger initiative through the Department of Medicine global health educational programming. It prepares individuals in many disciplines to direct discussions about advance care planning and to provide end-of-life care using core values of compassion and cultural humility.

Projects and Resources

The state of Minnesota lacks data on racial disparities specific to palliative care. However, we know that racial disparities exist in palliative care received at the end of life through hospice. Based on 2017 data, hospice utilization for Medicare beneficiaries in Minnesota was 53% for White beneficiaries compared to 38% for Black, 42% for Asian, and 50% for Hispanic/Latino/Latina/Latinx Minnesotans. The American Indian population had the lowest rate of utilization at 29% (MNHPC analysis of Medicare data).

To address barriers to advance care planning, the Center of American Indian and Minority Health and the University of Minnesota, Duluth has produced a culturally driven Health Care Directive, helping to identify medical decision makers, and inviting responses to encourage end of life discussions and planning using culturally safe tools. Another recent project in Central Minnesota, funded by the Morgan Family Foundation, aimed to create a culturally responsive Somali Health Care Directive. With this funding, Light the Legacy engaged Somali community leaders and advance care planning experts to co-develop a Draft Somali Health Care Directive.

Twin Cities Medical Society Foundation (TCMSF), the philanthropic arm of the Twin Cities Medical Society (now Advocates for Better Health), provides grants to local organizations working to advance health equity and in 2021 awarded to nine different organizations that support diverse and underserved communities. Although funded programs and services were not specifically targeting palliative care, these organizations impact

Minnesotans with life limiting and serious illness, like Phillips Neighborhood Clinic (A UMN Academic Health Center student-run clinic providing free health care services to the Phillips Neighborhood in south Minneapolis); or RoundtableRx, Minnesota’s Medication Repository Program, which provides low or no-cost prescriptions to patients in need.

The Minnesota Medical Association (MMA) has identified key policy issues impacting patients and physicians and patients through advocacy on crucial issues affecting the health of Minnesotans and the practice of medicine. A sample of these items are:

- **Improved Health Equity:** Minnesota has some of the largest health disparities for people of color. The MMA is dedicated to shining a light on this issue and closing that gap. [Minnesota Medical Association Health Equity Tools & Resources \(www.mnmed.org/advocacy/Key-Issues/Health-Equity/Health-Equity-Tools-Resources\)](http://www.mnmed.org/advocacy/Key-Issues/Health-Equity/Health-Equity-Tools-Resources).
- **Professional Satisfaction:** The MMA is working to alleviate the administrative burdens that are the most common drivers of physician burnout and professional dissatisfaction. The MMA champions the medical profession and celebrates the art and humanity of caring for patients. [Minnesota Medical Association Physician Well-Being & Professional Satisfaction \(www.mnmed.org/advocacy/Key-Issues/Physician-Well-being\)](http://www.mnmed.org/advocacy/Key-Issues/Physician-Well-being).

Accessed from the MMA website on August 28, 2022.

This snapshot of projects and solutions includes only a sample of the innovation we are witnessing in Minnesota – work that will continue to benefit and support underserved and diverse populations. Much of this work would not be possible without the support of state departments, like the Minnesota Department of Health, which collects and reports current data, allowing businesses and organizations that serve Minnesotans to respond to the needs efficiently. As well, accessible resources which provide support for the community to ensure care continues to meet the needs, working closer to equity, are resources like [Conducting a Health Equity Data Analysis \(HEDA\) \(www.health.state.mn.us/data/mchs/genstats/heda/index.html\)](http://www.health.state.mn.us/data/mchs/genstats/heda/index.html), tailored for local health departments, but allows for the access and benefit of all organizations within the state to benefit from one another, “We all do better, when we all do better.” (Paul Wellstone)

Specific Recommendations for Palliative Care Providers

Lastly, the essential work ahead of the field of Palliative Care is to support patient engagement on all levels with a greater focus on underserved communities. The Center to Advance Palliative Care (CAPC) has recently released its recommendations: [CAPC Perspectives on State Opportunities to Improve Care of the Seriously Ill \(www.capc.org/documents/download/1038/\)](http://www.capc.org/documents/download/1038/).

Outlined are potentially high-impact opportunities to expand access to quality palliative care for people living with serious illness. Full recommendations can be found at: [Implementing Quality Measures for Accountability in Community-Based Care for People with Serious Illness: Proceedings of a Workshop. The National Academies Press \(https://nap.nationalacademies.org/read/25202/chapter/1\)](https://nap.nationalacademies.org/read/25202/chapter/1).

Recommendations that support advancing the work of Palliative Care as it pertains to diverse communities are of particular interest to the Council:

- **Reported quality measures that are relevant to the population with serious illness** (or better yet, include such measures in value-based payment and financial incentive arrangements)
- **Growing the Primary and Specialty Palliative Care Workforce**
- **Increasing Public and Provider Awareness of Palliative Care**
- **Ancillary Opportunities to Support More Seamless Palliative Care Delivery**
 - Preserving and expanding access to telehealth, including all the surrounding considerations (e.g., increase broadband access, provision of devices, supporting interstate practice of medicine – as long as there are appropriate patient protections) that are being championed outside of specialty palliative care
 - Growing investment in direct care and community health workers

Next Steps

The Council’s prior Legislative Annual Report identified four recommended actions as the roadmap for the Council setting the policy stage to advance palliative care in Minnesota. Those recommended actions were:

1. **Submit** the Palliative Care Advisory Council’s proposed **definition** of Palliative Care to state legislators this session for action.
2. **Draft a recommended core set of palliative care services** for Minnesota.
3. **Collaborate with stakeholders**, such as the Department of Health Services (DHS), **to identify and align palliative care payment models to a recommended set of core palliative care services.**
4. **Request** the appropriate state agenc(ies) conduct a **comparative cost** study (both quantitative and qualitative measures) **based on recommended palliative care payment models.**

As 2022 ends, the Council celebrates an accomplishment of recommended action #1: an updated / corrected definition of Palliative Care made it through the legislative process and was signed into law effective 8/1/2022.

The bulk of this year’s report reflects the Council’s efforts toward recommended action #2: define a recommended core set of palliative care services for Minnesota. The Council developed this report using both federal¹ and state² specific success stories and lessons learned from those states that have advanced palliative within their jurisdiction, predominantly through waivers through their Medicaid programs.

As the Council focuses on the 2023, our efforts will focus on collaboration as we seek to validate recommendations with those partners connected to health care.

The Council recognizes the power of data and a comparative cost study – using Minnesota specific health care data – as the Council seeks to identify the impact palliative care could have through cost savings, cost avoidance and improvements to quality of life.

The Council recognizes that having a defined set of palliative care services is important – however progress will not happen without increasing palliative care within the medical workforce through education and training and leveraging palliative care to improve health equity and build trust within Minnesota’s diverse communities. .

The Council also recognizes that public awareness is critical. As long as lack of awareness and confusion exists around what palliative care is and isn't, the effectiveness of palliative care will be less than it could be, leaving patients and caregivers receiving less support than is needed.

The Council is once again grateful again for the continued support, collaboration, and partnerships with the Center to Advance Palliative Care, the Serious Illness Action Network, the Minnesota Network of Hospice and Palliative Care (MNHPC), Stratis Health and the Minnesota Alliance for Ethical Healthcare, and the American Cancer Society Cancer Action Network.

The Council looks forward to the next steps on the journey toward providing quality palliative care with access to all Minnesotans.

¹ Federal resources used in the creation of this report include but are not limited to *The National Academy for State Health Policy (NASHP)*, the *Center to Advance Palliative Care (CAPC)*, the *National Hospice and Palliative Care Organization*, *The Coalition to Transform Advanced Care (C-TAC)*.

² States sharing their palliative care journeys include *Arizona, California, and Hawaii*.

Appendix A: Summary of 2023 Key Recommendations

Recommended Actions

1. Continue with actions supporting the four recommendations from the 2023 Annual Legislative Report:
 - 1) **COMPLETED – effective 8/1/2022.** *Submit the Palliative Care Advisory Council’s proposed definition of Palliative Care to state legislators this session for action.*
 - 2) **IN PROGRESS – CONTINUE DURING 2023.** Draft a recommended core set of palliative care services for Minnesota. Review with key stakeholders.
 - 3) **IN PROGRESS – CONTINUE DURING 2023.** Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
 - 4) **TO BE DEFINED DURING 2023.** Request the appropriate state agency(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.
2. Extend the Council’s sunset date from 2025 to 2035 allowing the Council to continue the policy, education, training, awareness, and diversity efforts to be developed, implemented, and stabilized for Minnesotans.

New Education / Training / Awareness Recommendations

1. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
2. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
3. Require medical schools to include minimum standards for primary palliative care education for all students.
4. Require physician residencies to include minimum standards for primary palliative care education for all residents.
5. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

New Diversity, Equity, and Inclusion Recommendations

1. **Reported quality measures that are relevant to the population with serious illness** (or better yet, include such measures in value-based payment and financial incentive arrangements)
2. Growing the Primary and Specialty Palliative Care Workforce
3. Increase Public and Provider Awareness of Palliative Care
4. Provide Ancillary Opportunities to Support More Seamless Palliative Care Delivery

- a. Preserving and expanding access to telehealth, including all the surrounding considerations (e.g., increase broadband access, provision of devices, supporting interstate practice of medicine as long as there are appropriate patient protections) that are being championed outside of specialty palliative care
- b. Growing investment in direct care and community health workers

Appendix B: Summary of 2021 Key Recommendations

This summary does not include all the identified recommendations but rather identifies the few key recommendations for 2021 as follows:

1. Consider revising the language in 144.75A Subdivision 12 to eliminate the exclusive association of palliative care with hospice care.
2. Adopt the suggested definition of Palliative Care for Minnesota. *(See Definition Section for suggested language.)*
3. Enable Minnesota’s Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions using existing CPT or HCPCS codes.
4. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.
5. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the “loaded miles” benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
6. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.
7. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent, and young adult, and perinatal.
8. Rethink how technology can support those with serious illness care.
9. Develop a registry for provider orders for life-sustaining treatment (POLST) and advance care planning (ACP) documentation.
10. Improve access to and support for the use of technology for patients and caregivers.
11. Normalize and proactively support ACP as part of health care delivery.
12. Support workforce development and confidence in technology use for remote care delivery.
13. Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care.
14. Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP.
15. Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients.
16. Improve access to and consumer experience for all needed care service – primary, specialty care, and hospital care. (see the Health Equity Section for a list.)

17. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the “loaded miles” benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
18. Request research on rural transportation challenges affecting access to timely, appropriate health care (including palliative care).

Appendix C: Summary of 2020 Key Recommendations

During 2019, the Palliative Care Advisory Council identified the following 19 recommendations to improve and strengthen palliative care within Minnesota.

1. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.
2. Fund a statewide public education campaign around serious illness.
3. Fund a statewide public education campaign around end-of-life care.
4. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).
5. Fund efforts to train professionals in primary palliative care.
6. Fund efforts to train professionals in specialty palliative care.
7. Support innovative certification opportunities for mid-career providers who want to focus in palliative care including tele-education and mentorship programs.
8. Establish or expand reimbursement programs for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Worker, Chaplain, Child Life Specialist).
9. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
10. Require medical schools to include minimum standards for primary palliative care education for all medical students.
11. Require physician residencies to include minimum standards for primary palliative care education for all residents.
12. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.
13. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.
14. Expand access to home-based palliative care.
15. Expand access to pediatric palliative care in all settings to reduce the gap in services.
16. Establish a state-wide interdisciplinary palliative care research center or hub.

17. Require state regulatory agencies to develop measures, collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.
18. Encourage Minnesota based palliative care programs to participate in currently established national data collection efforts such as the Center to Advance Palliative Care National Palliative Care Registry.
19. Establish minimum standards for what constitutes a palliative care program with attention to challenges faced by different types of providers.

Appendix E: Recommended Readings from the Diversity, Equity, and Inclusion Workgroup

Jones KF, Laury E, Sanders JJ, Starr LT, Rosa WE, Booker SQ, Wachterman M, Jones CA, Hickman S, Merlin JS, Meghani SH. **Top Ten Tips Palliative Care Clinicians Should Know About Delivering Antiracist Care to Black Americans.** *J Palliat Med.* 2022 Mar;25(3):479-487.

Literature Review Health Care for Black Patients with Serious Illness. Center to Advance Palliative Care. 2021.

Community Voices for Health. Somali Perspectives on COVID-19 in Minnesota. *University of Minnesota, Program in Health Disparities Research.*

https://med.umn.edu/sites/med.umn.edu/files/072921_final_flyer_0.pdf

Fletcher, Faith E., Ray, Keisha S., Brown, Virginia A., Smith, Patrick T. **Addressing Anti-Black Racism in Bioethics: Responding to the Call.** Hastings Center Report. A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue. Volume 52, Issue S1. <https://doi.org/10.1002/hast.1360>

Sederstrom, Nneka, Lasege, Tamika. **Anti-Black Racism as a Chronic Condition.** Hastings Center Report. A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue. Volume 52, Issue S1. <https://doi.org/10.1002/hast.1364>

Overstreet, Nicole M. **Toward Critical Bioethics Studies: Black Feminist Insights for a Field “Reckoning” with Anti-Black Racism.** Hastings Center Report. A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue. Volume 52, Issue S1. <https://doi.org/10.1002/hast.1372>