

## 2019 Final Report

### The Coalition for Palliative Care

#### EXECUTIVE SUMMARY

Palliative care is a proven effective strategy to improve the quality of care and quality of life for seriously ill individuals. Palliative care services are delivered alongside curative treatment and often include pain and symptom management, care coordination, and team-based services. While this “model enjoys strong support among practitioners and patients, fewer than five percent of individuals who could benefit from palliative care receive it”.<sup>1</sup> Several of the Coalition Members have personally experienced the benefits of a quality palliative care program. Additionally, from the extensive presentations, the Coalition Members have learned that palliative care is often misunderstood, mis-defined, not broadly available, and where available underutilized. Accordingly, the Coalition for Palliative Care believes that urgent action is needed. As a result of our deliberations in 2019, the Coalition respectfully submits the following recommendations:

#### **Recommendation 1**

- *Define supportive and palliative care in code. Supportive and palliative care means an interdisciplinary team-based process designed to relieve suffering and improve quality of life for patients and families facing serious though not necessarily terminal illness. This care should be available at any stage of illness from birth to advanced age and may be offered simultaneously with disease modifying interventions, including attempts to cure or remission. Hospice care, on the other hand, is reserved for when curative treatments have been exhausted and patients have less than six months to live.*

#### **Recommendation 2**

- *Establish guidelines and criteria regarding when a program constitutes a palliative care program including but not limited to the education/training for all members of the interdisciplinary team including but not limited to the following: physicians, mid-level practitioners, nurses, social workers, counselors, and pharmacists. Recommend that each facility, including but not limited to a long-term care, nursing home, assisted living, long term acute care of 50 or more beds have a supportive and palliative care program.*

#### **Recommendation 3**

- *Establish evidence-based best practices for palliative care providers. These evidence-based practices should be individualized and patient-centered so that patient values and goals guide their treatment. When developing these best-practices the following items should be considered:*
  - *Assemble the interdisciplinary team;*
  - *Assess unmet need for supportive and palliative care;*

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<sup>1</sup> Trish Riley, Kitty Pruington, States Chart A Policy Path to Improve Palliative Care Services Across the Care Continuum, Health Affairs, August 3, 2019 citing Medicaid, A Small Share of Enrollees Consistently Accounted for a Large Share of Expenditures, U.S. Government Accountability Office, May 2015.

- *Educate members of the interdisciplinary team on principles and practices of supportive and palliative care, including communication skills;*
- *Collaborate with other specialists as necessary;*
- *Implement shared decision-making for current and advance care planning for future options;*
- *Welcome, support and involve the family in the care process to the extent desired by the patient;*
- *Create structures to make proxies, advance directives and portable medical orders available and actionable across care settings;*
- *Provide the right care, to the right person at the right time;*
- *Screen and manage pain and symptoms;*
- *Assess psychological and spiritual needs and address needs;*
- *Proactively identify and manage patients at high-risk for frequent hospital readmission*

**Recommendation 4**

- *The Bureau for Medical Services shall design and implement palliative care benefits for a wide range of beneficiaries including: fee-for-service, managed care, and via a state plan amendment, include but not be limited to eligibility for any individual at any age who is currently or expected to experience declining health, or is diagnosed with chronic, complex, or terminal illness. The services include physical and counseling treatment, pain and stress relief, referral to community resources, practical supports, and advance care planning.*

**Recommendation 5**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall evaluate impact of using of existing CPT codes for billing for some individual palliative care services through available CPT codes.*

**Recommendation 6**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall incorporate palliative care quality access metrics into value-based purchasing contracts. The purpose of value-contracting to improved performance by the provider. This form of contracting any payment holds a provider accountable for the cost and quality of health care.*
- *The Bureau for Medical Services and the Public Employees Insurance Agency shall incorporate palliative care into value driven delivery systems (e.g. ACO, health homes, delivery system reform incentive payment program (DSRIP)). In order to enhance the quality of palliative care delivery it can be tied to state health reform initiatives. For example, DSRIP palliative care metrics could include the percentage of patients indicating need who were offered or provided: An intervention for pain symptoms experienced during the past week; An intervention for physical symptoms (other than pain) experienced during the past week; An intervention for not feeling at peace during the past week; Intervention for depressive feelings experienced during the past week; or An intervention when there was no advance directive in place.*

### **Recommendation 7**

- *Increase education and awareness among stakeholders, including patients, families, providers, and payees through the development of a portal to centralize the names of licensed providers of palliative care to be maintained by the Office of Health Facility Licensure and Certification in a searchable format. Create educational materials to be distributed to patients, families and providers to raise awareness regarding palliative care services. These educational materials shall be developed work groups from this Coalition to work on these educational materials.*

### **Recommendation 8**

- *Create education materials to increase awareness regarding the importance of palliative care to be distributed to palliative care patients and to be available in provider offices. This information shall be developed by the Bureau of Public Health, the Center for End of Life Care and in conjunction with interested stakeholders.*

### **Recommendation 9**

- *Restore funding to the Center for End of Life Care in an annual amount of approximately \$600,000. The elimination of this funding in 2016 has jeopardized the mission and education and its ability to act as originally intended—a resource on palliative care and end of life care. Prior to this loss of funding West Virginia was a national leader in palliative care education and has the highest completion rate of advance directives in the country. Since this loss of funding advance directives have decreases by 50%. The work of the Center for End of Life Care permits providers to support patients at critical times. Based upon the results of the survey conducted by the Center, we know that more West Virginians need to be educated about the availability of palliative care since only 23% of individuals knew the definition of community palliative care without being provided a definition of this service.*

### **Recommendation 10**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall evaluate the development of alternative payment models for supportive and palliative care. The existing payment structure is insufficient to pay for supportive and palliative care service. For example, fee-for-service payments that are currently available for physicians for chronic case management and non-face-to-face services are insufficient to support high-quality supportive and palliative care services for patients with advanced illness, multiple chronic conditions, and/or functional limitations. Additionally, billing for supportive and palliative care delivered by non-billing clinicians (social work, pharmacists, or spiritual advisers) is generally available only through hospice, which would require a patient to forgo many treatment services. Accordingly, in order to support palliative care, benefit an alternative payment model must be developed. The Centers for Medicare and Medicaid Services has a demonstration of the Seriously Ill Payment (SIP) model scheduled to launch in 26 states in January 2020. This model recognizes that fee-for-service is a poor fit for the intensive, coordinated care needed for people living with serious illness. It is designed to serve only as a time limited intervention that provides increased financial resources to clinically stabilize patients with serious illness who exhibit a pattern of care fragmentation. Palliative care clinicians will be eligible to provide care for SIP beneficiaries by partnering with*

*primary care practices that are participating in the model. The payment is a one-time payment for the first visit plus a monthly professional population-based payment plus a flat visit fee plus a quality payment adjustment. West Virginia is not participating in this demonstration. The following areas are: Alaska (statewide), Arkansas (statewide), California (statewide), Colorado (statewide), Delaware (statewide), Florida (statewide), Greater Buffalo Region (New York), Greater Kansas City Region (Kansas and Missouri), Greater Philadelphia Region (Pennsylvania), Hawaii (statewide), Louisiana (statewide), Maine (statewide), Massachusetts (statewide), Michigan (statewide), Montana (statewide), Nebraska (statewide), New Hampshire (statewide), New Jersey (statewide), North Dakota (statewide), North Hudson-Capital region (New York), Ohio and Northern Kentucky Region (statewide in Ohio and partial state in Kentucky), Oklahoma (statewide), Oregon (statewide), Rhode Island (statewide), Tennessee (statewide), and Virginia (statewide).*

#### **Recommendation 11**

- *Develop education and teaching criteria for supportive palliative care to be used in an educational setting for providers, including but not limited to physicians, nurses, therapists, social workers, and pharmacists.*

#### **Recommendation 12**

- *Encourage private employers and state employers to engage medical, nursing, and social work schools to increase interest in the palliative care profession. There is a shortage of specialty palliative care physicians and the nation won't recover until 2045<sup>2</sup> without policy change, including the passage of the Palliative Care and Hospice Education and Training Act. Address burnout and support resilience, expand graduate medical education funding for palliative medicine training and opportunities for advanced training for all clinical disciplines; and support additional research into workforce capacity and growth of non-physician palliative care specialty care clinicians.*

#### **Recommendation 13**

- *Amend requirement contained in W.Va. Code §30-1-7a which specifies specific boards must establish continuing education requirements in their respective discipline on diversion training, best-practice prescribing of controlled substance training and prescribing and administration of an opioid antagonist for each person issued a license or certificate to include boards of all members of the supportive and palliative care interdisciplinary team. This requirement shall further be amended to reflect a one-time 3 hour continuing education requirement on the topic of supportive and palliative care patient for all members of the interdisciplinary team to be completed by their second license renewal date or within four years. The Coalition recommends this shall be counted toward the training required in W.Va. Code §30-1-7a.*

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<sup>2</sup> Arif H. Kamal, Policy Changes Key to Promoting Sustainability and Growth of the Specialty Palliative Care Workforce, Health Affairs, June 2019.

## **INTRODUCTION**

### **History and Creation of the Coalition.**

The Coalition for Palliative Care was created by act of the Legislature during the 2018 Regular Session of the West Virginia Legislature. The Coalition was proposed in House Bill 4035. That bill was introduced on January 12, 2018. It was first referred to the Committee on Health and Human Resources with a second reference to the Committee on the Judiciary.

House Bill 4035 was taken up, discussed, amended and passed by the Committee on Health and Human Resources on January 17, 2018. The changes made by the Committee on Health and Human Resources were primarily to include two certified hospice practitioners as members of The Coalition. The Committee on the Judiciary considered the bill on January 23, 2018. That committee made minor changes to the bill and reported the bill for consideration by the full House of Delegates.

Following the committee process, the bill was read a first time on January 24, 2018, and a second time on January 25, 2018. The bill was read a third time on January 26, 2018 in the House and passed. The bill was advanced to the Senate for consideration.

Upon receipt of the bill in the Senate, the bill was referred to the committee on Health and Human Resources with a second reference to the Committee on the Judiciary. The Committee on Health and Human Resources took up the bill, discussed, amended and passed the bill on February 27, 2018. The amendment made by the Committee on Health and Human Resources made technical modifications to the bill and title. The bill was reported out of that committee onto the second reference. The Committee on the Judiciary considered the Committee Substitute for House Bill 4035 and passed it as amended including the title amendment on March 3, 2018 and reported the bill for consideration by the full Senate.

The Senate read the bill a first time on March 5, 2018. The bill was read a second time on March 6, 2018 with a committee amendment, which was adopted by voice vote. It was read a third time on March 7, 2018 and passed Senate with amended title (Roll No. 384).

The House of Delegates received Senate message on March 9, 2018 and the House concurred in the amendment made by the Senate and passed the bill (Roll No. 486). The bill was enrolled and reported to the Governor on March 16, 2018 for his consideration. On March 22, 2018, the Governor signed the bill into law. A copy of the Enrolled Version of the Committee Substitute for House Bill 4035 is attached to this report as Exhibit "A".

### **Overview of the Legislation.**

The bill created an Advisory Coalition on Palliative Care (Coalition). The purpose for creation of the Coalition is to improve quality and delivery of patient centered and family focused palliative care in West Virginia.

The members of the Coalition are appointed by the President of the Senate and the Speaker of the House of Delegates. The bill further sets out the membership on the Coalition to include 1) a physician who practices palliative care in this state and is licensed pursuant to the provisions of W.Va. Code §30-3-1 *et seq.*, who shall serve as chair of the coalition for the first meeting until a chairman is selected by the Coalition; 2) a physician; 3) a registered professional nurse; 4) a social worker; 5) a pharmacist; 6) a spiritual advisor; 7) a patient advocate; 8) a family caregiver advocate; 9) one additional palliative care

practitioner; and 10) the Executive Director of the Center for End of Life Care, or his or her designee. The co-chairs of the Joint Committee on Health serve as nonvoting members, ex-officio. Membership is required to have at least one member from each Congressional District.

The Coalition is given the cooperation of the Department of Health and Human Resources, the West Virginia Insurance Commission, the Public Employees Insurance Agency, the Center for End of Life Care and all other entities of state government in the exchange of data, information and expertise, including, but not limited to providing the entity's plans to improve palliative care, sharing information on the financial impact of palliative care on the State of West Virginia, providing an assessment of the benefits of implemented programs and activities aimed at bettering palliative care, assisting in the development or revision of detailed action plans to improve palliative care, and providing resources required to implement the plan.

The administrative functions of the Coalition are the responsibility of staff assigned to the Joint Committee on Health.

The bill provides that the Coalition terminate on December 31, 2021.

#### **Overview of the Duties of the Coalition**

West Virginia Code §16-55-5 *et seq.* provides that the Coalition is tasked with the following duties:

1. Meet at least quarterly or at the call of the chairman.
2. Keep accurate records of the actions of the coalition.
3. Make recommendations and provide guidance to the Legislature on potential statutory solutions relative to regulation of palliative care.
4. Establish workgroups and clinical advisory committees as the coalition deems necessary to address pertinent issues related to palliative care and to provide consistency in the development of further regulation.
5. Consult with entities and persons with a particular expertise as the coalition deems necessary in the fulfillment of their duties. This can include public and private sector partnerships.
6. Establish a system for identifying patients or residents who could benefit from palliative care.
7. Provide information about and facilitate access to appropriate palliative care.

The Coalition is to offer any additional guidance to the Legislature which the Coalition sees is within its scope which would further enhance the palliative care.

In addition to these duties, the Coalition is required to report its findings to the Joint Committee on Health by December 31, 2019, and annually thereafter until the Coalition terminates. The report of the Coalition is required to include conclusions and recommendations to promote a better means for palliative care and provide recommendations for statutory and regulatory modifications for palliative care. Additionally, the report should identify any action which may be taken by the Legislature to better

foster awareness of palliative care issues in this state including a means to raise palliative care awareness. The report may also contain any other ancillary issues relative to palliative care.

### **Membership of the Coalition**

Pursuant to West Virginia Code §16-55-4, a letter dated November 20, 2018, signed by both Roger Hanshaw, Speaker of the House of Delegates and the Mitch Carmichael, President of the Senate was sent to prospective members of the Coalition. Each prospective member agreed to serve. The content of that letter is listed below:

### **Re: State Advisory Coalition on Palliative Care**

Dear:

You are hereby appointed to the State Advisory Coalition on Palliative Care effective immediately. This coalition was created by the passage of House Bill 4035 during the 2018 legislative session to improve quality and delivery of patient centered and family focused palliative care in West Virginia.

Your perspective, expertise and contributions will help the Legislature create and further develop relevant palliative care policies to help the citizens of our state. The Legislature is grateful that you are willing to share your time and your talents.

Please email your preferred contact information to [charles.roskovensky@wvhouse.gov](mailto:charles.roskovensky@wvhouse.gov). The first meeting of the coalition will be at a later date, and a meeting notice will be sent by email. If you have any questions, please do not hesitate to contact Charles Roskovensky by phone at 304-340-3338 or at the above email address.

Sincerely,

Mitch Carmichael  
President  
West Virginia Senate

Roger Hanshaw  
Speaker  
West Virginia House of Delegates

The initial membership included the following individuals:

1. Dr. Amy Wirts, Chair of the Coalition
2. Dr. Joshua Dower
3. Dr. Nikki Cole
4. Dr. Krista Capehart
5. Dr. Lori Constantine
6. Ron Hicks

7. George Ann Blough
8. Jane Marks
9. Vickie Powell
10. Reverend Greg Creasy

Of note, Reverend Creasy resigned from the Coalition on May 31, 2019. We are currently looking for a qualified spiritual leader to serve in his place. Additionally, Ron Hicks has resigned. Ron Hicks' vacancy has been filled by Katherine "Katie" Border.

West Virginia Code §16-55-3 requires that the staff assigned to the Joint Committee on Health provide administrative assistance to the Coalition. Currently that includes:

SENATE STAFF:

Cindy Dellinger, Counsel to the Senate for Health and Human Resources; and  
Terri Varney, Legislative Analyst to the Senate Committee on Health and Human Resources.

HOUSE OF DELEGATES STAFF:

Charlie Roskovensky, Counsel to the House of Delegates for Health and Human Resources;  
Jes Russo, Legislative Analyst to the House of Delegates Committee on Health and Human Resources; and  
Martha White, Secretary to the House of Delegates Committee on Health and Human Resources.

**STATISTICAL DATA REGARDING PALLIATIVE CARE**

The American Board of Medical Specialties recognizes the subspecialty of Hospice and Palliative Medicine (HPM) in a number of medical specialties including psychiatry, neurology, internal medicine, family medicine, pediatrics, surgery, emergency medicine, and obstetrics and gynecology. There are approximately 24 physicians with this subspecialty certification practicing in West Virginia as of June 2019.

In 2019<sup>3</sup>, the Center to Advance Palliative Care (CAPC) conducted a state-by-state analysis of palliative care services. This is an important initiative because they argue that palliative care improves care quality, lowers cost and people want it. Their report describes the prevalence of hospital based palliative care programs using data from the American Hospital Association Annual Survey, the National Palliative Care Registry, and CAPC's Mapping Community Care Initiative. As of 2019, 72% of hospitals with fifty or more beds report a palliative care team up from 67% in 2015 and 7% in 2001. West Virginia scored a "C" on this report. In West Virginia, the prevalence of hospitals that have a palliative care program is 56.5% or 13/23 reporting programs. The highest majority of these services are provided in a "not for profit" setting.

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<sup>3</sup> America's Care of Serious Illness, A State by State Report Card on Access to Palliative Care in our Nation's Hospitals, 2019



## COALITION MEETINGS

### January 4, 2019

The Coalition first met on January 4, 2019, at the West Virginia Capital. The meeting was primarily procedural. The members were welcomed by Cindy Dellinger, Counsel for Senate Committee on Health and Human Resources. Ms. Dellinger provided an overview of the legislation which created the Coalition and reviewed the charge as set out in statute and the expectations of the Legislature.

There were two (2) presenters at this meeting. The first presenter was Juliana Frederick-Curry, West Virginia Government Relations Director with American Cancer Society Cancer Action Network. Ms. Frederick-Curry began her discussion by defining palliative care. She indicated that palliative care treats the patient as well as the disease and provides patients and caregivers and extra layer of support making available a team of experts focused on relieving pain, managing emotional stress and providing other supportive services. She further indicated that palliative care services support patients from the point of diagnosis throughout treatment and beyond. Additionally, she indicated that palliative care improves the patient's quality of life by reducing pain and other symptoms and addressing the patient's goals. Palliative care treats pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and any other symptoms that may be causing distress. In a report, conducted in 2015, entitled "America's Care of Serious Illness" all 50 states were rated on access to Palliative Care. The overall United States score was a "B". In this same report, West Virginia scored a "C". Most regions saw growth in the number of palliative care programs. Two-thirds of hospitals with 50 or more beds reported to have palliative care teams. Although there has been considerable growth in the number of hospital and community-based palliative care programs in West Virginia, there are still barriers that have prevented all patients and families facing a serious illness from having access to palliative care programs and services. Specific barriers including the following:

- Lack in practicing health care professionals trained in the medical subspecialty of palliative care;
- Too few palliative care programs established in West Virginia hospitals and communities; and
- Lack in education about palliative care for active medical professionals (both in primary care and specialty settings), patients, and families.

A copy of the presentation and any supporting documents are attached as Exhibit "B" of this report.

The second presenter was Alvin H. Moss, MD with WVU Sections of Nephrology & Palliative Medicine, and West Virginia Center for End-of-Life Care. Dr. Moss discussed in detail community palliative care and the reasons it is preferred by the citizens of this state. He defined palliative care as specialized medical care for people with a serious illness, appropriate for any age and at any stage in illness, provided along with curative treatment, and with a goal of relieving symptoms and stress. He indicated that most individuals do not know what community palliative care is, but once it is explained, most want that type of care. According to Dr. Moss, West Virginians prefer quality of life to quantity of life; prefer comfort to life-prolong measures at the end of life; want communication and control over their future medical treatment; willing to complete advance directive and POST forms; want a 24/7 system that allows them to be treated at home; and want to die at home. A copy of the presentation and any supporting documents are attached as Exhibit "C" of this report.

There was also a discussion regarding future meeting topics, speakers and dates. At the conclusion of the meeting, it was determined that the next meeting would be scheduled after completion of the 2019 Legislative Session and the topic of discussion would be reimbursement.

**April 12, 2019**

The second meeting of the Coalition occurred in Charleston, West Virginia at the West Virginia State Capitol. During the meeting, members heard from Charlotte Stover, Director of Operations for the Public Employees Insurance Agency (PEIA) regarding the coverage and benefits currently being offered by PEIA and Humana. Ms. Stover also discussed the current challenges of the palliative care programs and identified care and medical needs that were not covered by medical insurance. Ms. Stover indicated that any policyholder or dependent covered by the plan is covered. She further indicated that the PEIA PPB plan covered active and non-Medicare retirees. She indicated that Humana is the Medicare Advantage Plan covering Medicare primary retirees. The benefits include care provided by home health care nurses and aids; prescriptions, oxygen, durable medical equipment, home physician visits, physical therapy, counseling and limited ambulance transportation. Non-covered services include custodial care services such as: meal preparation, personal hygiene services, sitters, bedside commodes/diapers, stair lift and transportation to medical appointments.

Ms. Stover reported that the challenges she sees in a palliative care program are adequate housing, non-medical related needs, family or caregiver support, home physician visits are not available in many areas and transportation. A copy of Ms. Stover's presentation is attached as Exhibit "D" of this report.

Members also heard from L. Alice Clay, RN, Program Manager for Hospice, Home & Private Duty Nursing Programs, Bureau for Medical Services, Department of Health and Human Resources. Ms. Clay explained the following differences between palliative care and hospice care:

- Palliative care is for individuals at any stage of a serious illness and their condition does not have to be incurable. Palliative care focuses on treatment of the illness.
- Hospice care is for individuals who are terminally ill and whose remaining lifespan is estimated at six months or less. Hospice care focuses on end-of-life care and comfort measures – NOT treatment.

She indicated that West Virginia Medicaid has no community palliative care rates or specific community palliative care services covered. She indicated that treatment components of palliative care are covered in a number of areas and are physician driven. She indicated that eligibility is limited to defined populations or medical necessity and the focus is on treatment not coordination or extra support. For example, home health must meet medical necessity, personal care must meet a defined number of deficits and aged and disabled waiver must meet functional deficits for nursing home level of care. She further indicated that in the West Virginia Medicaid program palliative care is virtually synonymous with hospice care.

A copy of Ms. Clay's presentation is attached as Exhibit "E" of this report.

**May 10, 2019**

The third meeting of the Coalition occurred in Charleston, West Virginia at the West Virginia State Capitol. Andrea Moore, Project Manager with Quality Insights addressed the Coalition, via video conference, to explain the purpose and development of Phase I of their Pathways Project collaborative. Quality Insights established the Coalition for Supportive Care of Kidney Patients in 2003. The Coalition promotes integrations of patient-centered palliative care into the continuum of care for patients with kidney disease, from diagnosis through end-of-life and bereavement. In 2016, Quality Insights received funding to conduct a 15-month planning project to improve supportive care for patients with kidney disease.

Ms. Moore identified primary supportive care as being synonymous with palliative care. Their Pathways Project team preferred the term “supportive care.” Supportive care involved services aimed at improving the quality of life throughout the continuum of life-limiting illness; helped patients cope with living, as well as dying, regardless of life expectancy; and interdisciplinary to address holistically the needs of patients and families. The skill sets for primary supportive care include the following:

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about prognosis, goals of treatment, suffering and code status

Specialty supportive care is a separate level of care that manages more complex and challenging cases. The skills set for specialty supportive care are listed below:

- Management of refractory pain or other symptoms
- Management of more complex depressions, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment within families, between staff and families and/or among treatment teams
- Assistance in addressing cases of near futility

After their research, planning and development, they created evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease. Specifically, those recommendations are detailed below:

#### Supportive Care Capacity (*Create the System*)

- Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
- Assess unmet supportive care needs in patient population
- Provide education to staff on the principles and practices of primary supportive care, including communication skills
- Collaborate with palliative care/hospice specialists

#### Values Guide Care (*Elicit & Respect Patient Values and Preferences*)

- Implement shared decision-making for current and advance care planning for future care options
- Welcome support and involve family in the care process to the extent desired by patient
- Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings

Just Right Care (*The Right Care to the Right Person at the Right Time*)

- Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions
- Provide medical management without dialysis to patients avoiding or delaying dialysis
- Screen and manage pain and symptoms
- Assess psychological and spiritual needs and address needs
- Proactively identify and manage patients at high-risk for frequent hospital readmission

Throughout the Continuum (*Enhanced Support at the End of Life*)

- Coordinate care and care transitions with specialty palliative care and hospice
- Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients

Key Evidence-Based Recommendations:

1. Assemble an interdisciplinary team for setting with a day-to-day leader and champion(s)
2. Prioritize ill patients with CKD and ESRD for primary and specialty supportive care interventions
3. Implement shared decision making for current and advance care planning for future options
4. Coordinate care and care transitions with specialty palliative care and hospice

Key take-away points from the information provided by Ms. Moore are:

1. The need for supportive care has never been greater and is increasing at a rapid pace
2. Prioritize professional education and training in primary supportive care core competencies for all clinicians
3. Increasing public awareness and education on supportive care
4. Supportive care is most effective when offered and considered early in the course of illness
5. Improving access and utilization of supportive care requires the integration of services into the structure and financing at all levels of healthcare systems

A copy of Ms. Moore's presentation is attached as Exhibit "F" of this report.

Dr. Emily Jaffe, MD, Highmark West Virginia's Vice President and Executive Medical Director along with Jim Fawcett, President of Highmark WV presented information regarding palliative care in West Virginia, the services provided and the challenges. Highmark WV provides comprehensive coverage for medically necessary services. Palliative care services that may be part of a treatment plan could be eligible for coverage if the specific service is covered. Examples of palliative care services include:

- Primary care
- Home health care
  - Supplies
  - Prescription drugs
  - Oxygen
  - Social services
  - Home health aide
  - Physical therapy
  - Occupational therapy

- Laboratory tests
- Infusion therapy
- Case management services may also be eligible for assisting with the coordination of care, transportation and access to community resources.

There are limitations to coverage. Palliative Care Services may require prior authorization and could be subject to visit limits as defined in the member's certificate book. Custodial care services, personal hygiene, convenience items (such as lift chairs, diapers, exercise equipment), and transportation for convenience or due to lack of transportation are not covered services.

Highmark Health identifies its palliative care initiatives as follows:

1. Identify members that can benefit from palliative care upstream.
2. Incent collaboration between PCPs, specialists, health care delivery partners and payers to develop alternative payment models that drive quality, are member centric and help members achieve their goal of home-based services where possible.
3. Utilize robust data collection, tracking and sharing to demonstrate the value and impact of palliative care programs.
4. Educate, campaign of awareness and culture of change, mandatory training and use of Center to Advance Palliative Care (CAPC) tools.

From the perspective of a health insurer, Dr. Jaffe felt that the West Virginia's strengths in palliative care were 1) POST: odds ratio of outside hospital death 2.33, odds ratio of admission to hospice 2.69; 2) the West Virginia Health Information Network; 3) the Palliative Care Coalition; and 4) FQHCs and Provider Systems committed to population health. She identified the challenges in West Virginia as 1) geography (patients living in rural areas); 2) health status of the patients; 3) social determinants of health; 4) access to services; and 5) focus on palliative.

A copy of Dr. Jaffe's presentation is attached as Exhibit "G" of this report.

Coalition member, Josh Dower, MD addressed the members and provided a description of a business model for palliative care using Aspire Healthcare as an example. He discussed various payment models and did not provide any handouts.

#### **June 14, 2019**

The fourth meeting of the Coalition occurred in Charleston, West Virginia at the West Virginia State Capitol. Rachel Donlon, MPH, National Academy for State Health Policy, addressed the members via teleconference. NASHP received funding from The John A. Hartford Foundation to focus on identifying opportunities and challenges for states to advance palliative care programs/policies. They wanted to explore how each state was supporting palliative care services, both in hospitals and communities, through their roles as licensors, regulator, payers and conveners. With respect to palliative care and the states, there is a triple aim to: improve the individual experience of care, improve the health of populations, and reduce the per capita costs of care for populations. Their research revealed that the majority of states have not developed a comprehensive strategy to support palliative care. While NASHP found pockets of activity, there are opportunities for states to leverage available policy levers to:

1. Improve oversight

The current national landscape reveals eight states defines palliative care and/or set standards of care outside of hospice regulations; seven states have palliative care related requirements for health care facilities; four states require providers to share palliative care information with patients.

State opportunities:

These opportunities include: creating palliative care definitions and/or standards that do not limit care to hospice programs and leveraging state licensing for hospitals and other health care facilities to require palliative care education, referrals and service deliver.

For example, Massachusetts has implemented a number of policies and regulations to enhance access to palliative care. The state defines palliative care in public health care law. The state requires licensed health care facilities and providers to provide information on palliative care to appropriate patients. Additionally, ACO certification standards require formal partnerships with palliative care and hospice providers. There is also a one-time CME requirement on end-of-life care.

Additionally, Maryland defined palliative care in health care facility regulations. Further, health care facility regulations mandate that hospitals with more than 50 beds have a palliative care program, including standards on staffing, education/training, available services, etc.

2. Build workforce capacity

Currently seven states require provider training related to palliative care, end-of-life care and pain management.

State Opportunities

Opportunities to advance workforce capacity include: engage provider associations to promote training and mentorship opportunities; engage medical, nursing, social work schools; and implement continuing medical education and other training requirements.

For example, in California, physicians must complete a one-time requirement of 12 CME hours on pain management and care for the terminally ill by the second license renewal date or within four years. Additionally, California combines state and federal Medicaid administrative matching funds to contract with CSU's Institute for Palliative Care to offer palliative training to Medicaid providers/staff.

3. Strengthen coverage and reimbursement under Medicaid and State Employee Health Plans

For individuals with serious illnesses, they found eight states, which have incorporated a specific, stand-alone palliative care benefit into Medicaid state plan, managed care or medicaid managed care long-term services and supports (MLTSS) contracts, PACE, duals demos. Seven states reported their state employee health plans offer palliative care benefits. States may reimburse for some individual palliative care services through available CPT codes.

### State Opportunities

Opportunities include developing and/or implementing home and community based services and state plan options, developing and/or implementing MLTSS contracts, developing and/or implementing health homes, developing and/or implementing dual eligible special needs plans, developing and/or implementing the managed care Program for All-Inclusive Care for the Elderly (PACE), and developing or enhancing state employee health plan purchasing. Additional opportunities include developing pathways for specialty palliative care services, utilizing existing billing codes and leveraging existing managed care contracts.

For example, Arizona has implemented palliative care benefits for a wide range of Medicaid beneficiaries in fee for service, managed care, and MLTSS. Eligibility is provided to any individual (at any age) who is currently or expected to experience declining health, or is diagnosed with a chronic, complex or terminal illness. Services covered include: 1) physical and/or behavioral health treatment; 2) pain and stress relief; 3) referrals to community resources (e.g. counseling); 4) practical supports (non-billable services provided by family member or caregiver to assist or perform functions); and 5) advanced care planning.

In California, the state leveraged open Medicaid billing codes to reimburse for palliative care services such as advance care planning, palliative care assessment and consultation, pain and symptom management, plan of care, care coordination, and palliative care team.

#### 4. Enhance the quality of palliative care services

Five states have embedded palliative care related metrics or quality improvement initiatives into state health reform initiatives.

### State Opportunities

Opportunities to advance this in West Virginia are to leverage managed care contracting, incorporate palliative care quality/access metrics into value-based purchasing, and incorporate palliative care into value-driven delivery systems (e.g. Affordable Care Organizations, health homes, Delivery System Reform Incentive Payment Program (DSRIP))

For example, in New York's DSRIP performing provider system waiver the networks must include a minimum of five transformations projects, with at least two focusing on clinical improvement. Palliative care is one of eight clinical improvement options. There are five associated metrics related to integrating palliative care into the broader health care continuum. The DSRIP palliative care metrics included the percentage of patients indicating need who were offered or provided: an intervention for pain symptoms experienced during the past week; an intervention for physical symptom (other than pain) experienced during the past week; an intervention for not feeling at peace during the past week; intervention for depressive feelings experienced during the past week; an intervention where there was no advance directive in place.

#### 5. Encourage a culture shift in how palliative care is viewed and delivered

Fifteen states have legislation requiring public health agencies to develop and disseminate resources about palliative care.

### State Opportunities

Opportunities include increasing awareness among stakeholders, including patients, families, and providers; creating educational resources; compiling and/or facilitating referral networks; and operating palliative care programs.

### Key Considerations

Incentivize evidence-based practices;  
Leverage interdisciplinary care team to support all domains of care; and  
Develop policies and regulations with various settings in mind.

A copy of Rachel Y. Donlon's presentation is included as Exhibit "H".

### **August 16, 2019**

The fifth meeting of the Coalition occurred in Charleston, West Virginia at the West Virginia State Capitol. Jacqueline M. Kocinski, MPP, Director, Health Policy & Government Relations, Phil Peterson, MD, and Phil Rodgers, MD, all with the American Academy of Hospice and Palliative Medicine (AAHPM) addressed the members via teleconference. Ms. Kocinski indicated that AAHPM's core mission is to expand access of patients and families to high-quality palliative care and advance the discipline of hospice and palliative medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy. AAHPM's public policy priorities are ensuring timely and effective access to prescription medication for patients with medically appropriate indications and advancing palliative care in national quality measurement and performance improvement strategies to ensure a focus on high-value patient and family-centered outcomes across the continuum of care.

In order to deliver high-quality care for patients, there must be a focus on advancing policies that grow hospice and palliative care workforce. Numerous studies have shown the high-quality palliative care services can provide significant benefit to patients including the following: reducing pain and suffering, reducing the use of low-value treatment services, reducing stress and physical burden on caregivers that can worsen their health, reducing the number of hospital admissions for exacerbations or complications, reducing the number of times the patient will visit the emergency room. There is currently a shortage of physicians with a specialty in hospice and palliative medicine (HPM).

Ms. Kocinski discussed an article in Health Affairs entitled "Policy Changes Key to Promoting Sustainability and Growth of the Specialty Palliative Care Workforce", June 2019 which indicates modeling using 2018 clinician data indicates that there is an impending workforce valley with declining physician numbers that will not recover to the current 2019 level until 2045. This will result in a physician to patient ratio of 1:1380 up 71%. The authors of this article make five policy recommendations: pass the palliative care and hospice education and training act at a federal level; expand GME funding for palliative care medicine training and opportunities for advanced training for all clinical disciplines, support additional research into workforce capacity and growth of non-physician care specialty clinicians, advance payment models that support the full interdisciplinary team and address burnout.

Dr. Peterson discussed details of the palliative care and hospital education and training act and other key pieces of federal legislation including the rural access to hospice act, improving access to medicare coverage act and health professionals bill. He further discussed the importance of mid-career



and innovative training. Dr. Rodgers discussed payment issues. Currently, patients who have serious, potentially life-limiting illnesses or multiple chronic conditions coupled with functional limitations are not well-served by the current fragmented, intervention-oriented health care system. Patients are frequently admitted to the hospital because of the lack of home and community based services.

Dr. Peterson, explained that palliative care highlights weaknesses in the fee for service (FFS) payment methodology. For example, he explained FFS encourages the excessive use of low-value services, has insufficient incentives to improve quality and has poor coordination of care. Accordingly, he indicated, despite the proven benefits of palliative, many patients do not receive it because current payment systems do not provide adequate resources to enable palliative care teams to deliver those services to the right patient in the right place at the right time. He explained under the current FFS system, payments available to physicians for chronic care management for patients with advanced illness are insufficient to support high quality palliative care services for patients with advanced illness, multiple chronic conditions and/or functional limitations. Additionally, payment for palliative care and support services delivered by non-billing clinicians (nursing, social work, pharmacist, spiritual care professionals) is generally only available to patients through a hospice benefit, which requires a patient to forgo many treatment services.

Accordingly, AAPHM submitted an alternative payment model, Patient and Caregiver Support for Serious Illness (PACSSI) model to CMS for approval. This demonstration model is to launch in 26 states in January 2020. Payment amounts for patients will be set to reflect the high need, high-risk nature of the population as well as include an increase or decrease in payment based on quality.

A copy of Jacqueline Kocinski, Dr. Peterson, and Dr. Rodgers's presentation is included as Exhibit "I".

#### **October 25, 2019**

The sixth meeting of the Coalition occurred in Charleston, West Virginia at the West Virginia State Capitol. James M. Mears, MD, Assistant Professor of Family Medicine, WVU Charleston, addressed the members. He indicated that the purpose of a hospital based palliative care program is to assist with advance care planning, discuss goals of care, manage pain and symptoms in cancer patients, prevent readmissions to the hospital, decrease the patient length of stay, and evaluate cost savings. He indicated that the challenges of hospital palliative care programs are funding, lack of trained professionals, recruitment, time, burnout, and outpatient follow-up. Based upon facility specific demographics, cancer was the highest percentage (43.2%) of patients receiving palliative care treatment.

A copy of Dr. Mear's presentation is included as Exhibit "J".

#### **November 15, 2019 and December 13, 2019**

The Coalition met to discuss finalization of the Coalition report. During the December 13, 2019 meeting, the Coalition members approved the report for submission to the Legislature.

#### **COALITION RECOMMENDATIONS**

Based upon the meetings and deliberations of the Coalition, an initial draft of 13 recommendations was developed for consideration. Those final recommendations include the following:

### **Recommendation 1**

- *Define supportive and palliative care in code. Supportive and palliative care means an interdisciplinary team-based process designed to relieve suffering and improve quality of life for patients and families facing serious though not necessarily terminal illness. This care should be available at any stage of illness from birth to advanced age and may be offered simultaneously with disease modifying interventions, including attempts to cure or remission. Hospice care, on the other hand, is reserved for when curative treatments have been exhausted and patients have less than six months to live.*

### **Recommendation 2**

- *Establish guidelines and criteria regarding when a program constitutes a palliative care program including but not limited to the education/training for all members of the interdisciplinary team including but not limited to the following: physicians, mid-level practitioners, nurses, social workers, counselors, and pharmacists. Recommend that each facility, including but not limited to a long-term care, nursing home, assisted living, long term acute care of 50 or more beds have a supportive and palliative care program.*

### **Recommendation 3**

- *Establish evidence-based best practices for palliative care providers. These evidence-based practices should be individualized and patient-centered so that patient values and goals guide their treatment. When developing these best- practices the following items should considered:*
  - *Assemble the interdisciplinary team;*
  - *Assess unmet need for supportive and palliative care;*
  - *Educate members of the interdisciplinary team on principles and practices of supportive and palliative care, including communication skills;*
  - *Collaborate with other specialists as necessary;*
  - *Implement shared decision-making for current and advance care planning for future options;*
  - *Welcome, support and involve the family in the care process to the extent desired by the patient;*
  - *Create structures to make proxies, advance directives and portable medical orders available and actionable across care settings;*
  - *Provide the right care, to the right person at the right time;*
  - *Screen and manage pain and symptoms;*
  - *Assess psychological and spiritual needs and address needs;*
  - *Proactively identify and manage patients at high-risk for frequent hospital readmission*

### **Recommendation 4**

- *The Bureau for Medical Services shall design and implement palliative care benefits for a wide range of beneficiaries including: fee-for-service, managed care, and via a state plan amendment, include but not be limited to eligibility for any individual at any age who is currently or expected to experience declining health, or is diagnosed with chronic, complex, or terminal illness. The*

*services include physical and counseling treatment, pain and stress relief, referral to community resources, practical supports, and advance care planning.*

**Recommendation 5**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall evaluate impact of using of existing CPT codes for billing for some individual palliative care services through available CPT codes.*

**Recommendation 6**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall incorporate palliative care quality access metrics into value-based purchasing contracts. The purpose of value-contracting to improved performance by the provider. This form of contracting any payment holds a provider accountable for the cost and quality of health care.*
- *The Bureau for Medical Services and the Public Employees Insurance Agency shall incorporate palliative care into value driven delivery systems (e.g. ACO, health homes, delivery system reform incentive payment program (DSRIP)). In order to enhance the quality of palliative care delivery it can be tied to state health reform initiatives. For example, DSRIP palliative care metrics could include the percentage of patients indicating need who were offered or provided: An intervention for pain symptoms experienced during the past week; An intervention for physical symptoms (other than pain) experienced during the past week; An intervention for not feeling at peace during the past week; Intervention for depressive feelings experienced during the past week; or An intervention when there was no advance directive in place.*

**Recommendation 7**

- *Increase education and awareness among stakeholders, including patients, families, providers, and payees through the development of a portal to centralize the names of licensed providers of palliative care to be maintained by the Office of Health Facility Licensure and Certification in a searchable format. Create educational materials to be distributed to patients, families and providers to raise awareness regarding palliative care services. These educational materials shall be developed work groups from this Coalition to work on these educational materials.*

**Recommendation 8**

- *Create education materials to increase awareness regarding the importance of palliative care to be distributed to palliative care patients and to be available in provider offices. This information shall be developed by the Bureau of Public Health, the Center for End of Life Care and in conjunction with interested stakeholders.*

**Recommendation 9**

- *Restore funding to the Center for End of Life Care in an annual amount of approximately \$600,000. The elimination of this funding in 2016 has jeopardized the mission and education and its ability to act as originally intended—a resource on palliative care and end of life care. Prior to this loss of funding West Virginia was a national leader in palliative care education and has the highest completion rate of advance directives in the country. Since this loss of funding advance directives*

have decreases by 50%. The work of the Center for End of Life Care permits providers to support patients at critical times. Based upon the results of the survey conducted by the Center, we know that more West Virginians need to be educated about the availability of palliative care since only 23% of individuals knew the definition of community palliative care without being provided a definition of this service.

#### **Recommendation 10**

- *The Bureau for Medical Services and the Public Employees Insurance Agency shall evaluate the development of alternative payment models for supportive and palliative care. The existing payment structure is insufficient to pay for supportive and palliative care service. For example, fee-for-service payments that are currently available for physicians for chronic case management and non-face-to-face services are insufficient to support high-quality supportive and palliative care services for patients with advanced illness, multiple chronic conditions, and/or functional limitations. Additionally, billing for supportive and palliative care delivered by non-billing clinicians (social work, pharmacists, or spiritual advisers) is generally available only through hospice, which would require a patient to forgo many treatment services. Accordingly, in order to support palliative care, benefit an alternative payment model must be developed. The Centers for Medicare and Medicaid Services has a demonstration of the Seriously Ill Payment (SIP) model scheduled to launch in 26 states in January 2020. This model recognizes that fee-for-service is a poor fit for the intensive, coordinated care needed for people living with serious illness. It is designed to serve only as a time limited intervention that provides increased financial resources to clinically stabilize patients with serious illness who exhibit a pattern of care fragmentation. Palliative care clinicians will be eligible to provide care for SIP beneficiaries by partnering with primary care practices that are participating in the model. The payment is a one-time payment for the first visit plus a monthly professional population-based payment plus a flat visit fee plus a quality payment adjustment. West Virginia is not participating in this demonstration. The following areas are: Alaska (statewide), Arkansas (statewide), California (statewide), Colorado (statewide), Delaware (statewide), Florida (statewide), Greater Buffalo Region (New York), Greater Kansas City Region (Kansas and Missouri), Greater Philadelphia Region (Pennsylvania), Hawaii (statewide), Louisiana (statewide), Maine (statewide), Massachusetts (statewide) Michigan (statewide), Montana (statewide) Nebraska (statewide), New Hampshire (statewide), New Jersey (statewide), North Dakota (statewide), North Hudson-Capital region (New York), Ohio and Northern Kentucky Region (statewide in Ohio and partial state in Kentucky), Oklahoma (statewide), Oregon (statewide), Rhode Island (statewide), Tennessee (statewide), and Virginia (statewide).*

#### **Recommendation 11**

- *Develop education and teaching criteria for supportive palliative care to be used in an educational setting for providers, including but not limited to physicians, nurses, therapists, social workers, and pharmacists.*

#### **Recommendation 12**

- *Encourage private employers and state employers to engage medical, nursing, and social work schools to increase interest in the palliative care profession. There is a shortage of specialty*

*palliative care physicians and the nation won't recover until 2045<sup>4</sup> without policy change, including the passage of the Palliative Care and Hospice Education and Training Act. Address burnout and support resilience, expand graduate medical education funding for palliative medicine training and opportunities for advanced training for all clinical disciplines; and support additional research into workforce capacity and growth of non-physician palliative care specialty care clinicians.*

### **Recommendation 13**

- *Amend requirement contained in W.Va. Code §30-1-7a which specifies specific boards must establish continuing education requirements in their respective discipline on diversion training, best-practice prescribing of controlled substance training and prescribing and administration of an opioid antagonist for each person issued a license or certificate to include boards of all members of the supportive and palliative care interdisciplinary team. This requirement shall further be amended to reflect a one-time 3 hour continuing education requirement on the topic of supportive and palliative care patient for all members of the interdisciplinary team to be completed by their second license renewal date or within four years. The Coalition recommends this shall be counted toward the training required in W.Va. Code §30-1-7a.*

Submitted by:

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Coalition on Palliative Care

Members of the Coalition on Palliative Care:

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<sup>4</sup> Arif H. Kamal, Policy Changes Key to Promoting Sustainability and Growth of the Specialty Palliative Care Workforce, Health Affairs, June 2019.