



Working together to improve health care quality, outcomes, and affordability in Washington State.

Palliative Care

2019

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Executive Summary

People with serious or advanced illness often experience increases in symptoms coupled with a decrease in function. Traditional life-prolonging or curative care often does not meet a person's range of needs as illness progresses. Palliative care, as defined by the National Consensus Project, *"focuses on expert assessment and management of [symptoms including] pain...assessment and support of caregiver needs, and coordination of care [attending] to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness."* Provision of palliative care consistently shows improved outcomes for patients in both in- and out-patient settings. However, many patients who would benefit from palliative care do not receive this service. Access issues stemming from lack of workforce, lack of referrals, and lack of a sustainable business model contribute to low utilization rates.

While palliative care grew out of the hospice movement, palliative care is distinct from hospice care and applicable to a wider population. Palliative care can be offered alongside curative treatment at any age or stage of illness and can address many unmet patient needs.

The workgroup developed the following focus areas to increase accessibility and quality of palliative care:

- Defining palliative care using the standard definition developed by the National Consensus Project including appropriateness of primary and specialty palliative care.
- Spreading awareness of palliative care.
- Clinical best practice provision of palliative that is:
 - Responsive to local cultural needs,
 - Includes advance care planning as outlined in the 2014 Bree Collaborative [End-of-Life Care Report and Recommendations](#) including appropriateness of an advance directive and Physician Orders for Life-Sustaining Treatment (POLST), and
 - Incorporates goals of care conversations into the medical record and plan of care.
- Availability of palliative care through revision of benefit structure such as a per member per month (PMPM) benefit.

These recommendations present steps for adoption for individual stakeholder groups including patients and family members, specialty palliative care, health care systems, health plans, and the Washington State Health Care Authority on pages 5-11. Palliative care is further defined on pages 12-14 including information on best practices for spreading awareness, clinical components of high-quality palliative care, differences between primary and specialty palliative care, and when to refer to specialty palliative care. Goals of care conversations are discussed on page 15 and reimbursement strategies are outlined on pages 16-17. Finally, quality metrics are outlined on page 16-17.

These recommendations aspire to support people with serious illness and their families by moving toward a defined, high-quality, and sustainable palliative care infrastructure.

Dr. Robert Bree Collaborative Background

The Dr. Robert Bree Collaborative was established in 2011 by Washington State House Bill 1311 “...to provide a mechanism through which public and private health care stakeholders can work together to improve quality, health outcomes, and cost effectiveness of care in Washington State.” The Bree Collaborative was named in memory of Dr. Robert Bree, a leader in the imaging field and a key member of previous health care quality improvement collaborative projects.

Members are appointed by the Washington State Governor and include public health care purchasers for Washington State, private health care purchasers (employers and union trusts), health plans, physicians and other health care providers, hospitals, and quality improvement organizations. The Bree Collaborative is charged with identifying health care services annually with substantial variation in practice patterns, high utilization trends in Washington State, or patient safety issues. For each health care service, the Bree Collaborative identifies and recommends best-practice, evidence-based approaches that build upon existing efforts and quality improvement activities to decrease variation. In the bill, the legislature does not authorize agreements among competing health care providers or health carriers as to the price or specific level of reimbursement for health care services. Furthermore, it is not the intent of the legislature to mandate payment or coverage decisions by private health care purchasers or carriers.

See **Appendix A** for a list of current Bree Collaborative members.

Recommendations are sent to the Washington State Health Care Authority for review and approval. The Health Care Authority (HCA) oversees Washington State’s largest health care purchasers, Medicaid and the Public Employees Benefits Board Program, as well as other programs. The HCA uses the recommendations to guide state purchasing for these programs. The Bree Collaborative also strives to develop recommendations to improve patient health, health care service quality, and the affordability of health care for the private sector but does not have the authority to mandate implementation of recommendations.

For more information about the Bree Collaborative, please visit: www.breecollaborative.org.

Bree Collaborative members identified palliative care as a priority improvement area and convened a workgroup to develop evidence-based standards. The workgroup met from January to November 2019.

See **Appendix B** for the Palliative Care Workgroup Charter and a list of members.

See **Appendix C** for results of the guideline and systematic review search.

Clinical Background

People with serious or advanced illness often experience increases in symptoms coupled with a decrease in function. Serious illness is a condition that *“negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress... [and] carries a high risk of mortality.”*¹ Traditional life-prolonging or curative care often does not meet a person’s range of needs as illness progresses. Fragmented care delivery and frequent transitions between care settings, unmet symptoms such as pain, and responsibilities put on family members and other caregivers create undue stress and burden.² Further, many people who would prefer to remain at home experience high-intensity care often in a hospital setting.³

Palliative care, that can be offered alongside curative treatment at any age or stage of illness, can address many of these deficits in our health care system.

*“Palliative care focuses on expert assessment and management of [symptoms including] pain...assessment and support of caregiver needs, and coordination of care [attending] to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness.”*⁴

Benefits

Provision of palliative care consistently shows improved outcomes for patients in both in- and out-patient settings.⁵ Palliative care has been associated with reduction in symptom burden, higher satisfaction with care, more appropriate referrals to hospice, and fewer days in a hospital.^{6,7} For patients with cancer, early delivery of palliative care has been associated with increased quality of life and with longer life.^{8,9} Use of supportive services like palliative care is associated with transition of end-of-life care from in-hospital to home.¹⁰ Palliative care reduces caregiver stress and has been shown to reduce caregiver emotional and spiritual needs as well as increasing caregiver confidence.^{11,12} For many diagnoses, patients who receive palliative care earlier on in the course of their disease have been shown to live longer and with a higher quality of life when compared to those who start palliative care later in the course of illness.^{9,13}

While palliative care grew out of the hospice movement, palliative care is distinct from hospice care and applicable to a wider population of people. Oncology care has been an earlier adaptor of providing palliative care, but access remains inconsistent within oncology and especially for other diagnoses. Palliative care is largely offered in larger, not-for-profit, urban hospital settings.¹⁴ In Washington State, 92% hospitals with greater than 300 beds have a palliative care program while 32% of those with fewer than 50 beds have a palliative care program.¹⁵ Among oncology patients within the Veterans Administration, 52% received palliative care and those who received care did so for a median of 38 days prior to death.¹⁶

Barriers to Access

Lack of adequate reimbursement serves as a primary barrier to adequate provision of palliative care. The interdisciplinary team, not all of whom can bill for services, and the emphasis on care occurring outside of face-to-face visits such as care coordination are not supported within a fee-for-service system. Further, many providers and patients lack knowledge or have misconceptions about palliative care. Barriers to referrals include lack of palliative care within a system, workforce shortages, provider lack of knowledge about existing resources, lack of knowledge about palliative care more generally, provider reluctance to refer (e.g., due to fear of upsetting patients or being perceived as abandoning patients), reluctance of the patient and family to be referred, and restrictive criteria for referral to palliative care.^{17,18} While oncologists have reported that palliative care is appropriate throughout a disease episode, they also report that lack of availability, too narrow of a clinical focus, and lack of clear divisions of responsibility as barriers to patient-centered care.¹⁹ Further, the structures, processes, and definition of palliative care are often lacking.

Our workgroup defined focus areas to support a common understanding of palliative care, support broader awareness, respond to individual patient and community need(s), and financially support palliative care with the following focus areas:

- Defining palliative care using the standard definition developed by the National Consensus Project including appropriateness of primary and specialty palliative care.
- Spreading awareness of palliative care.
- Clinical best practice provision of palliative that is:
 - Responsive to local cultural needs,
 - Includes advance care planning as outlined in the 2014 Bree Collaborative [End-of-Life Care Report and Recommendations](#) including appropriateness of an advance directive and Physician Orders for Life-Sustaining Treatment (POLST), and
 - Incorporates goals of care conversations into the medical record and plan of care.
- Availability of palliative care through revision of benefit structure such as a per member per month (PMPM) benefit.

Recommendations for Stakeholder Groups

The following pages present recommendations for individual stakeholder groups to increase access to high-quality palliative care. As reimbursement is a primary barrier for provision of palliative care, recommendations for Washington State's largest health care purchaser, the Health Care Authority, and for health plans are presented first.

These recommendations are not intended to be used in lieu of medical advice.

Washington State Health Care Authority and Department of Health

- **Partner with delivery systems, health plans, and others to consistently educate providers and the community.** Use the definitions within these recommendations from the National Consensus project for palliative care to serve as a leader in educating the population on the purpose, applicability, and value of palliative care.
 - Be consistent with talking about palliative care, do not define palliative care as how it is not hospice or use terms such as end of life, death, or dying. Use terms like *“living with a serious illness.”*
 - Use *“palliative care is based on need not prognosis.”*
 - Using a metaphor may be helpful in developing shared understanding with staff and patients such as at EvergreenHealth [here](http://www.evergreenhealth.com/palliative-care) (www.evergreenhealth.com/palliative-care). *“People with serious illnesses can feel as if they’re on a “medical train.” One test or treatment quickly leads to the next, and soon you can feel as though the train is speeding down the tracks. You’re not sure how you got there or what comes next. An EvergreenHealth Palliative Care consultation is like a stop at a train station. It’s a chance to get off the medical train, get comfortable, and plan the rest of the journey...”*
- Adopt the Bree Collaborative-endorsed National Consensus Project definition of palliative care as a standard across Washington State. Define palliative care outside of hospice regulation.
- Develop a baseline set of diagnoses and criteria for provision of palliative care aligned with the National Consensus Project Definition (e.g., offered based on need not prognosis not solely “life limiting illness”). See **Appendix D**.
- Absent a move to a per member per month (PMPM) reimbursement structure, implement reimbursement policies for licensed social worker (licensed under RCW 18.225.090(1)(a) or 18.225.145(1)(a)) home visits that include but are not limited to behavioral health codes (as patient need often extends beyond behavioral health).
- Provide a per member per month (PMPM) palliative care benefit for seriously ill patients for publicly-purchased health care that is open to all ages and follows a patient across settings (e.g., if hospitalized) and does not require the patient to be homebound or to stop curative or active therapy with the setting of provision of specialty palliative care services (e.g., hospital) as the accountable entity.
 - **Identification:** Develop an agreed-upon strategy to identify seriously ill patients (e.g., such as with the PACSSI Eligibility and Tiering Criteria outlined in **Appendix D**).

- **Interdisciplinary:** Require an interdisciplinary approach to care that does not require a physician to lead the interdisciplinary team.
- **Payment structure:** Offer a larger payment for the initial intake visit, a PMPM payment, and a smaller per-in-person visit payment.
- **Services:** Use recommendations on the following pages to define included specialty palliative care services and which services are excluded (e.g., hospitalizations).
- **Measure:** Measure success using at least one metric related to (1) potentially avoidable complications and (2) patient-specific quality of life. See page 18 for options under each of these categories. Metrics may be tied to gainsharing.

Health Plans

- Define seriously ill patients, see **Appendix D**. Those eligible for palliative care should not also be receiving hospice.
- Support provision of palliative care for seriously ill patients (i.e., in-patient, out-patient, home) concurrent life prolonging (e.g., curative, disease modifying).
- Do not include a home-bound requirement for home-based palliative care.
- Reimburse for telemedicine or telemonitoring care for seriously ill patients as defined in RCW 74.09.325 or RCW 74.09.658 (or more recent)
- Provide a per member per month (PMPM) palliative care benefit for seriously ill patients that is open to all ages and follows a patient across settings (e.g., if hospitalized) and does not require the patient to be homebound or to stop curative or active therapy with the setting of provision of specialty palliative care services (e.g., hospital) as the accountable entity.
 - **Identification:** Develop an agreed-upon strategy to identify seriously ill patients (e.g., such as with the PACSSI Eligibility and Tiering Criteria outlined in **Appendix D**).
 - **Interdisciplinary:** Require an interdisciplinary approach to care that does not require a physician to lead the interdisciplinary team.
 - **Payment structure:** Offer a larger payment for the initial intake visit, a PMPM payment, and a smaller per-in-person visit payment.
 - **Services:** Use recommendations on the following pages to define the included specialty palliative care services and which services are excluded (e.g., hospitalizations).
 - **Measure:** Measure success using at least one metric related to (1) potentially avoidable complications and (2) patient-specific quality of life. See page 18 for options under each of these categories. Metrics may be tied to gainsharing.

Health Care Purchasers (employers and union trusts)

- Prioritize palliative care services as part of the overall benefit structure.
- Encourage or collaboratively develop with delivery systems and/or plans demonstration projects offering concurrent palliative and curative care, see per member per month (PMPM) benefit as described above.
- Educate employees on the definition and benefit of palliative care through employing-facing materials or through integration into wellness programs.

Patients and Family Members

- Know who your primary care provider is and how to reach them.
- Talk about how well your needs and symptoms are being address and whether specialty palliative care may be better able to address your needs.
- Talk about your goals of care with your provider or care team. Your goals of care are typically the aspects of your life that are most important to you such as attending an upcoming wedding.
- If applicable, know who to contact on your care team with questions or urgent issues.
- **Advance Care Planning.** Think about the type of care you would want at the end of life and what aspects of care and your life are most important to you. Have a conversation with your family members or other caregivers about what you would want. You should also have a conversation with your care team about your values, goals and preferences for end-of-life care that includes caregivers and the individual designated as your durable power of attorney for health care.
 - Talk about how family members or other caregivers should implement the care plan if you are unable to express your wishes.
 - We recommend that you complete:
 - An advance directive that stipulates specific treatment preferences (if known and applicable to the situation),
 - A durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and
 - A written personal statement that articulates your values and goals regarding end-of-life care.
 - A Physician Orders for Life-Sustaining Treatment (POLST) form may be appropriate. These are completed with your physician and/or clinical team.
- Have conversations early on in disease progression about your wishes for hospital visits and medical intervention. Conversations should include risks and benefits of hospitalization and may include filling out a POLST. As part of these conversations, think about the type of care that you would or would not want (e.g., feeding tubes). Information from Choosing Wisely and Consumer Reports on feeding tubes can be found [here](http://www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/) (www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/).
- Be sure that you and your family or other caregivers understand red flags that may mean you need to go to the hospital and under what conditions you may not want to receive care in the hospital setting.
- Talk about the potential need for a higher level of care (e.g., more help at home) if care needs are greater than can be safely managed. Conversations should include financial as well as medical concerns.
- Connect to community resources or state resources that can help plan for future and increasing care needs including respite care.
- **For Caregivers.** Caregiving can be stressful. Talk to your or your partner/family member's provider about your needs as a caregiver. Resources for caregiving are available [here](http://www.aarp.org/caregiving/local/info-2017/important-resources-for-caregivers.html) (www.aarp.org/caregiving/local/info-2017/important-resources-for-caregivers.html).

Specialty Palliative Care Teams

Specialty palliative care teams can be located in hospital inpatient settings, outpatient clinics, hospice agencies, or in the community.

- **Champion palliative care within your organization.** Use the definitions within these recommendations from the National Consensus project for palliative care to educate providers within your system and the community on the purpose, applicability, and value of palliative care.
 - Be consistent with talking about palliative care, do not define palliative care as how it is not hospice or use terms such as end of life, death, or dying. Use terms like *“living with a serious illness.”*²⁰
 - Use *“palliative care is based on need not prognosis.”*
 - Using a metaphor may be helpful in developing shared understanding with staff and patients such as at EvergreenHealth [here](http://www.evergreenhealth.com/palliative-care) (www.evergreenhealth.com/palliative-care).

Outline steps for initial assessment and ongoing management collaboratively with organizational leadership, as follows:

- **Initial Assessment.** Assess and manage physical, functional, psychological, practical, and spiritual consequences of a serious illness. Our workgroup prioritizes the following domains: goals of care, advance care planning, cognitive impairment, functional needs, medical care, caregiver needs, behavioral health/psychosocial, and spiritual needs as listed:
 - Explaining diagnoses, prognosis and talk about setting expectations.
 - **Goals of care.** For all patients, discuss goals of care. Document in the medical record. Goals of care should be reassessed regularly as they may change over time.
 - Clarify patient goals around hospitalization and the potential for need for long-term care. Discuss possible red flags that may necessitate admission to an acute care setting as well as risks and benefits of hospitalization.
 - Discuss how to plan and prepare for a potential inpatient stay including risks and benefits of a hospitalization and when the patient may want to be hospitalized and when they may not want care in a hospital setting.
 - **Advance care planning.** Conduct advance care planning conversations as outlined in the 2014 Bree Collaborative [End-of-Life Care Report and Recommendations](#).
 - Document advance care planning discussions with easily understandable and culturally appropriate advance directives that include: a living will (also called a health care directive) that stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and a written personal statement that articulates the patient’s values and goals regarding end-of-life care. Use the following codes (which can be added to the Medicare Annual Wellness Visit).²¹
 - CPT Code 99497 *“Advance care planning including the explanation and discussion of advance directives such as standard forms (with*

completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.”

- CPT Code 99498 “Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes (List separately in addition to code for primary procedure).”
- **Cognitive impairment.** Assess for and address cognitive impairment, if present, using the recommendations outlined in the 2017 [Bree Collaborative Alzheimer’s Disease and Other Dementias Report and Recommendations](#).
- **Functional needs.** Discuss practical consequences of a serious illness such as difficulty with activities of daily living. Connect with community resources, as needed.
- **Symptom management/Medical care.** Assess and manage symptoms of serious illness that impact quality of life. Communicate with the patient’s primary care provider and/or specialty care, if possible.
- **Pharmacy management.** Assess medication list in conjunction with pharmacist, if possible.
- **Caregiver needs.** Assess caregiver stress, capacity, and support. Offer support, as available.
- **Behavioral health/psychosocial.** Assess and manage behavioral health symptoms.
 - Explain to patients the purpose of screening for depression, suicidality, and anxiety including the safety and security of the information. Screen for the following using a validated instrument:
 - Depression (e.g. Patient Health Questionnaire-2, PHQ-3 and/or PHQ-9) and anxiety (e.g., Generalized Anxiety Disorder-2). Follow guidelines within the 2017 [Bree Collaborative Behavioral Health Integration Report and Recommendations](#), or more recent if available.
 - Suicidality (e.g. ninth question of the PHQ-9, first and second questions of the Columbia Suicide Severity Rating Scale (C-SSRS), the Ask Suicide-Screening Questions (ASQ) as well as current plans and any past attempts). If suicide risk is detected, follow guidelines within the 2018 [Bree Collaborative Suicide Care Report and Recommendations](#), or more recent if available.
- **Spiritual care needs.** Assess and discuss spiritual care needs. Ideally this is done through a board-certified chaplain with specific training in palliative care, when available.
- **Other needs.** Discuss other patient needs that may not be described above.
- **Ongoing management.** Assess the above domains, as needed. Goals of care discussions and advance care planning may need to be reassessed due to changes in symptoms and/or diagnosis or prognosis.

Primary Care Providers and Sub-specialty Providers

- Provide primary palliative care. This may be done within regularly-scheduled care.
 - For Medicare recipients: The Annual Wellness Visit is billable at most annually per patient with HCPCS codes G0438 or G0439.
 - Explaining diagnoses, prognosis and talk about setting expectations.
 - Review the inclusions under specialty palliative care. Many of these can be provided within primary care or other specialty care including:
 - Initial Assessment. Assess and manage physical, functional, psychological, practical, and spiritual consequences of a serious illness.
 - Goals of care discussions.
 - Goals around hospitalizations or other in-patient stays.
 - Advance care planning as outlined in the 2014 Bree Collaborative [End-of-Life Care Report and Recommendations](#). Use the following codes (which can be added to the Medicare Annual Wellness Visit).²¹
 - CPT Code 99497 “Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.”
 - CPT Code 99498 “Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes (List separately in addition to code for primary procedure).”
 - Assessment for cognitive impairment as outlined in the 2017 [Bree Collaborative Alzheimer’s Disease and Other Dementias Report and Recommendations](#).
 - Functional needs.
 - Symptom management.
 - Pharmacy management.
 - Caregiver support.
 - Behavioral health (e.g., depression, anxiety, suicidality, substance use disorder).
 - Other needs (e.g., spiritual, if possible).
- Make sure that patients know how to contact their primary care provider and/or team with questions or urgent issues.
- If patient needs become greater than can be managed within primary care, consider referral to specialty palliative care.

Health Systems

- **Educate providers and staff.** Use the definitions within these recommendations from the National Consensus project for palliative care to educate providers within your system on the purpose, applicability, and value of palliative care.
 - Be consistent with talking about palliative care, do not define palliative care as how it is not hospice or use terms such as end of life, death, or dying. Use terms like *“living with a serious illness.”*
 - Use *“palliative care is based on need not prognosis.”*
 - Using a metaphor may be helpful in developing shared understanding with staff and patients such as at EvergreenHealth [here](http://www.evergreenhealth.com/palliative-care) (www.evergreenhealth.com/palliative-care).
- **Community.** Understand local community characteristics (e.g., language needs, religious background, cultural background) and local community resources. If possible, develop referral processes for relevant community resources (e.g., respite care).
- **Patient identification.**
 - Develop a common definition for serious illness within your organization. See **Appendix D**. This definition should be shared within the organization and with health plans. This definition may be developed into red flags or other indicators based on diagnosis in the EHR.
 - Patients who enter the system through the emergency department may be a good candidate for palliative care.
- **With a palliative care program.**
 - **Interdisciplinary team.** Define the members of the interdisciplinary team available to meet a patient’s medical, psychological, and spiritual care needs including in-home services where applicable. The interdisciplinary team should:
 - Designate a leader, not necessarily a physician.
 - Hold regular team meetings as defined by the team (e.g., weekly, bi-weekly).
 - Include nursing staff.
 - **Care Coordination.** Offer a care coordination function, either conducted by an individual or shared between team members.
 - **Care pathway.** Develop a care pathway outlining inclusions in an initial assessment and ongoing care as defined under specialty palliative care, above.
 - **Initial assessment.** Assess and address goals of care, advance care planning, cognitive impairment, functional needs, symptom management/medical care, caregiver needs, behavioral health/psychosocial needs, and spiritual needs.
 - **Ongoing care.** Continue to assess and manage patient and caregiver needs as appropriate.
 - **Urgent Issues.** Make sure that patients and their family caregivers know who and how to contact on the team with questions or urgent issues.
 - Access to the care team or to other specialty expertise that is connected to the care team 24 hours a day, 7 days a week is highly recommended, but may not be feasible in all areas.
- Update billing system to allow billing for advance care planning CPT Codes 99497 and 99498.

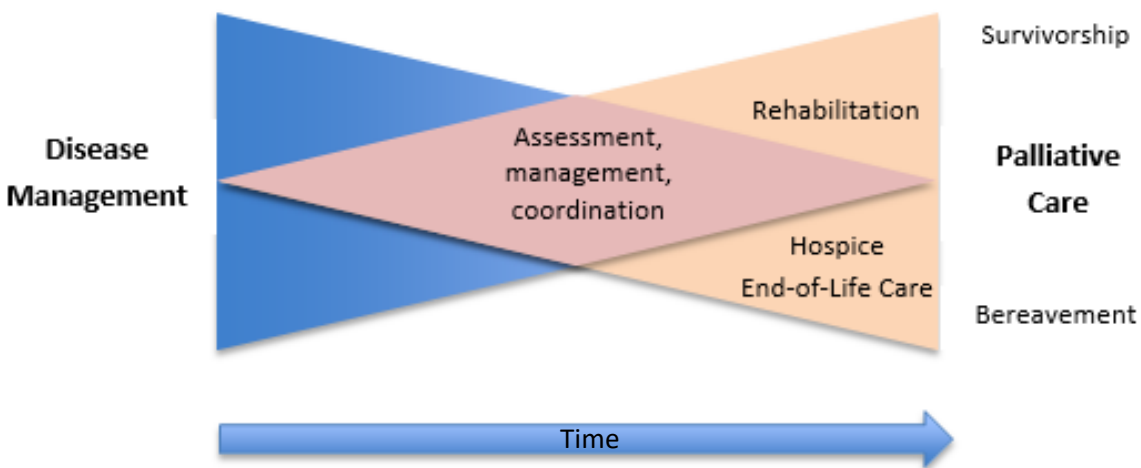
Defining Palliative Care

The workgroup adopted the definition of palliative care from the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. Available [here](http://www.nationalcoalitionhpc.org/npc/) (www.nationalcoalitionhpc.org/npc/), as follows:

“Palliative care focuses on expert assessment and management of [symptoms including] pain...assessment and support of caregiver needs, and coordination of care [attending] to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness.”

While hospice care is generally only available to people with six months or less to live, palliative care can be offered alongside life-prolonging or curative care.²² For some, palliative is followed by rehabilitation and survivorship. For others, palliative care leads to hospice and end-of-life care as shown in Figure 1.

Figure 1: Course of Palliative Care



Adapted from: Hawley P. Barriers to Access to Palliative Care. Palliat Care. 2017 Feb 20;10:1178224216688887.

Spreading Awareness

Lack of awareness and misunderstanding of palliative care are consistent barriers to access to care. The Centers to Advance Palliative Care (CAPC) have found that palliative care is poorly understood among the public, with 38% of adults over 25 years and 42% of adults over 65 years not being able to rate palliative care as either favorable or unfavorable due to lack of knowledge.²³ Barriers from the clinical side include perceiving patients as not wanting palliative care, not being comfortable talking about palliative care, and thinking of palliative care as only applicable at the end of life.²¹ Appropriate, consistent messaging is necessary to overcome misperceptions and lack of knowledge.

High-Quality Palliative Care

The National Consensus Project for Quality Palliative Care National Coalition for Hospice and Palliative Care [Clinical Practice Guidelines for Quality Palliative Care, 4th edition identifies](#) eight domains that comprise the ideal components of palliative care. The workgroup recognizes these components as the ideal definition of palliative care, but ideals that may be difficult to achieve in the current environment. The eight domains are as follows:

1. **Structure and Processes of Care.** Including defining the interdisciplinary team, outlining patient assessment, and elements of the care plan.
2. **Physical Aspects of Care.** Including management of physical symptoms of a serious illness.
3. **Psychological and Psychiatric Aspects.**
4. **Social Aspects of Care.** Including assessing and managing social support needs.
5. **Spiritual, Religious, and Existential Aspects of Care.**
6. **Cultural Aspects of Care.**
7. **Care of the Patient Nearing the End of Life.**
8. **Ethical and Legal Aspects of Care Content.** Including advance care planning.

Principles of high-quality palliative care that can be instituted in a variety of settings include interdisciplinary team-based care, increased access, concurrent delivery with curative or disease-modifying or directed treatment, appropriate patient population, medical and social support services, support for caregivers, and care coordination.²⁴

Primary Palliative Care

Many of the aspects of palliative care, including the patient needs described above, can and should be managed within primary care or other specialties such as cardiology, pulmonary, etc. with referrals to specialty palliative care when patient need increases beyond the capacity of primary palliative care.

Primary palliative care is care delivered within primary and relevant sub-specialty care (e.g., cardiology, others) to meet physical, functional, psychological, practical, and spiritual consequences of a serious illness. The majority of palliative care provided is primary palliative care.²⁵ In many cases, primary palliative care is simply good primary care that addresses the increase in symptoms that occur with progression of a serious illness. Basic communications with a patient and family member including explaining the diagnosis, prognosis and setting expectations, having a goals of care discussion, and

advance care planning can and should be done in primary care and in other specialties. Assessment and management of symptoms such as pain and medication management and interactions with caregivers including information about caregiver support can also be a part of primary palliative care.

When to Refer

Providers should refer to specialty palliative care when a patients' needs can no longer be met within the current setting. Increases in symptom burden, including but not limited to pain, nausea, delirium, fatigue, anorexia, anxiety, depression, are common with serious illness. While hospice has clear referral criteria, palliative care should be done at the discretion of the referring provider based on symptom burden and other palliative care needs being more than can be handled by current care.

Specialty Palliative Care

Specialty palliative care is provided by an interdisciplinary team that includes or has access to a care coordination function and is able to meet medical, psychosocial, and spiritual care needs. Specialty palliative care teams can be located in hospital inpatient settings, outpatient clinics, within hospice agencies or in the community. Access (e.g., telemedicine) to 24/7 specialty expertise is highly recommended.

Successful palliative care programs have common elements including integrated teamwork, pain and symptom management, holistic care, caring providers, care that is timely and responsive, and patient and family preparedness, meeting the definitions above.²⁶ The National Consensus Project defines the interdisciplinary team as a *"team of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, chaplains, and others based on need"* and breaks out professions by the following roles:

Physicians and/or advanced practice providers	Nurses	Social workers	Chaplains	Clinical pharmacists
Illness trajectory, prognosis, and medical treatments	Assessment, direct patient care, serving as patient advocate, care coordinator, and educator	Family dynamics, assess and support coping mechanisms and social determinants of health, identify and facilitate access to resources, and mediate conflicts	Spiritual care specialists, assess and address spiritual issues and help to facilitate continuity with the patient's faith community as requested	Medication management, adjustment and deprescribing

These are meant to serve as examples of how an interdisciplinary team may be structured.

Goals of Care Conversations

Goals of care conversations are clearly called out as a best practice during serious illness.² Many of the components of goals of care conversations are shared across palliative care and advance care planning generally, and thus are difficult to report separately. Goals of care conversations about serious illness care and end-of-life care are associated with patients' receipt of care that aligns with their wishes, higher quality of life, and lower stress among family members.²⁷ Patients surveyed have reported wanting to have goals of care conversations but expect providers to initiate the process.²⁸

Interventions on provider communication and on implementing goals of care discussions have been shown to be effective in guideline-concordant care and high-quality conversations.²⁹ Interventions focused on improving communication between providers and patients, mainly involving practice and feedback sessions, show higher patient ratings about communication and more information being obtained.³⁰ A goals of care intervention targeted to both patients and clinicians has been associated with a significant increase in goals of care conversations occurring, being documented in the medical record, higher-quality conversation, and higher concordance between a patient's stated goals and the care that a patient actually receives in patients with stable goals when compared with usual care.³¹

Best practices for goals of care conversations include: clearly discussing information on prognosis and certainty of prognosis as accurately as possible, talking about preferences for decision making including designating a durable power of attorney for health care, understanding fears related to serious illness, understanding patient and situation-specific goals (e.g., attending a granddaughter's wedding, walking around the block), discussing the impact of impaired function and trade-offs, and how to involve family members or others.³² Questions to ask include:³³

- Patient understanding: What is your understanding now of where you are with your illness?
- Information preferences: How much information about what is likely to be ahead with your illness would you like from me?
- Goals: If your health situation worsens, what are your most important goals?
- Fears: What are your biggest worries about the future and your health?
- Trade-offs: If you become sicker, how much are you willing to go through for the possibility of gaining more time?
- Family: How much does your family know about your priorities and wishes?

Reimbursement

While continuity of care over the life-span is the goal of the workgroup, a fully patient-centered system is not within the workgroup's scope. These recommendations are focused on palliative care with the acknowledgement that there will still be gaps in care due to fragmented healthcare reimbursement and policy.

Financial support for the diverse services offered under the umbrella of specialty palliative care is one of the largest barriers to patient access to care and standardization of care delivery between organizations. Many organizations support specialty palliative care through professional fees for a fee-for-service clinical encounter. Alternatively, there is a movement toward value-based reimbursement that could cover clinical encounters and non-clinical services such as care coordination or chaplains (e.g., bundled payment, per-member-per-month). The goals of reimbursement changes are to increase access to high-quality palliative care through incremental changes within the existing fee-for-service infrastructure or through new models of reimbursement.³⁴

Patient Population

Defining the patient population to whom receipt of palliative care services would provide value is necessary in developing an equitable health care system. Many organizations, including the Center to Advance Palliative Care, define palliative care as applicable at any age and any stage of serious illness based on need not prognosis or diagnosis.³⁵ Many care delivery organizations define diagnoses for which a palliative care referral is triggered while other models use a mix of diagnosis, functional status, and/or utilization. See **Appendix D: Defined Patient Population** for a list of possible definitions for the patient population. California Medicaid uses a floor definition of four diagnoses (i.e., cancer, congestive heart failure, chronic obstructive pulmonary disease, and liver disease) and managed care plans can offer palliative care services to additional groups.³⁶

Fee-for-Service

Changes within the existing fee-for-service environment acknowledge the need for incremental change.

- Reimbursement for nonclinical (i.e., those without prescribing ability) interdisciplinary team members.
- Reimbursement for care coordination or goals of care discussion without the patient.
- Changing hospice benefit to reimburse for palliative care.

Value-Based Reimbursement

Many of the value-based reimbursement models, including those through CMS, some state Medicaid agencies, and some pilots through commercial insurance, use a monthly case rate or per member per month.

Example from the Centers for Medicare and Medicaid Services:³⁷ In April 2014, CMS announced new payment models including Primary Care First High Need/Seriously Ill.

Washington State was not selected for this model. The Seriously Ill model applies to Medicare recipients with no primary care provider who have complex needs as defined by having a Hierarchical Condition Category (HCC) score >3; or HCC >2 with >2 hospitalizations in the last 12 months; and/or durable medical equipment claims for transfer equipment or a hospital bed. Participating practices will receive a one time payment for the first visit, a monthly per patient per month up to 12 months, a per-visit payment for each in-person visit with a clinician, and a quality adjustment based on performance.

Example from California Medicaid:³⁶ California State Senate Bill 1004 required the California Department of Health Care Services to “*establish standards and provide technical assistance for [Medicaid] managed care plans to ensure delivery of palliative care services*” for implementation in 2017. Eligible conditions include cancer, congestive heart failure, chronic obstructive pulmonary disease, and liver disease and managed care plans may also authorize palliative care for other conditions. Palliative care services include advance care planning, palliative care assessment and consultation, developing a plan of care, pain and symptom management, behavioral health, care coordination, chaplain services, recommended 24/7 telephonic palliative care, and access to curative or disease modifying care.

Quality Metrics

Comprehensive quality metrics for adults with serious illness need to be feasible, under the control of those being measured, reliable, and valid. The workgroup does not recommend specific metric and instead recommends that at least one metric be selected and utilized under (1) potentially avoidable complications and (2) patient-specific quality of life.

Potentially Avoidable Complications

Potentially avoidable complications with low difficulty of use using the serious illness population as the denominator include:³⁸

- Service utilization:
 - Number of emergency department visits
 - Number of hospitalizations
 - Readmissions in the last 30 days of life
 - Intensive care unit (ICU) admissions in the last 30 days of life
- Hospitalizations in the last 30 days of life
- Circumstances of death
 - Died in an acute care hospital
 - Died in an intensive care unit

Note: None of these metrics represent “never events” and may constitute the best care for individual patients. However, for a healthcare system, reducing this type of potentially avoidable complication on average can improve patient and family care.

Patient-Specific Quality of Life

The most commonly-used metric is the National Committee for Quality Assurance (NCQA) [Care for Older Adults](#). States, including Colorado, Illinois, and Rhode Island have included this metric in contracting and tied this to performance. This metric refers to “The percentage of adults 66 years and older who had each of the following during the measurement year” reported separately and cumulatively.

- Advance care planning
- Medication review
- Functional status assessment
- Pain assessment

Ideally this domain would include a patient-reported metric, however these can be difficult to implement. The [Palliative Care Outcome Scale](#) (IPOS) includes 10 items that assesses physical symptoms, psychological, emotional, and spiritual needs, is available in multiple languages, and can be completed by either a patient or with a provider. This tool is being used by New York State as a screening tool for palliative care.

Appendix A: Bree Collaborative Members

Member	Title	Organization
Susie Dade, MS	Deputy Director	Washington Health Alliance
Peter Dunbar, MB ChB, MBA (Vice-Chair)	CEO	Foundation for Health Care Quality
Gary Franklin, MD, MPH	Medical Director	Washington State Department of Labor and Industries
Stuart Freed, MD	Chief Medical Officer	Confluence Health
Richard Goss, MD	Medical Director	Harborview Medical Center – University of Washington
Sonja Kellen	Global Benefits Director	Microsoft
Dan Kent, MD	Chief Medical Officer, Community Plan	UnitedHealthcare
Wm. Richard Ludwig, MD	Chief Medical Officer, Accountable Care Organization	Providence Health and Services
Greg Marchand	Director, Benefits & Policy and Strategy	The Boeing Company
Robert Mecklenburg, MD	Medical Director, Center for Health Care Solutions	Virginia Mason Medical Center
Kimberly Moore, MD	Associate Chief Medical Officer	Franciscan Health System
Carl Olden, MD	Family Physician	Pacific Crest Family Medicine, Yakima
Drew Oliveira, MD	Executive Medical Director	Regence BlueShield
Mary Kay O'Neill, MD, MBA	Partner	Mercer
John Robinson, MD, SM	Chief Medical Officer	First Choice Health
Jeanne Rupert, DO, PhD	Provider	One Medical
Angela Sparks, MD	Medical Director Clinical Knowledge Development & Support	Kaiser Permanente Washington
Hugh Straley, MD (Chair)	Retired	Medical Director, Group Health Cooperative; President, Group Health Physicians
Shawn West, MD	Medical Director	Premiera BlueCross
Laura Kate Zaichkin, MPH	Director of Health Plan Performance and Strategy	SEIU 775 Benefits Group
Judy Zerzan, MD, MPH	Chief Medical Officer	Washington State Health Care Authority

Appendix B: Shared Decision Making Charter and Roster

Problem Statement

People with serious illness often have a range of needs that may not be met by life-prolonging or curative care. *“Palliative care focuses on expert assessment and management of [symptoms including] pain...assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness.”*¹ However, the structures, processes, and the definition of palliative care are lacking. Poor or lack of reimbursement for palliative care services alongside life-prolonging and/or curative care contributes to a lack of access. Palliative care has been associated with reduction in symptom burden, higher satisfaction with care, higher referrals to hospice, and fewer number of days in a hospital.^{2,3} For patients with cancer, early delivery of palliative care has been associated with increased quality of life.⁴

Aim

To develop best practice recommendations for palliative care regarding:

- Assessment of patients with serious illness for primary and/or specialty palliative care need,
- Care delivery frameworks, and
- Payment models to support delivery of care.

Purpose

To propose evidence-based recommendations to the full Bree Collaborative on:

- Defining care delivery pathways for interdisciplinary team-based palliative care including pain management, assessing patient and caregiver needs, and care coordination.
- Standard evaluation of patients with serious illness for primary or specialty palliative care need.
- Educational standards for primary care staff about palliative care.
- Integrating palliative care alongside life-prolonging and/or curative care.
- Payment models to support delivery of palliative care alongside life-prolonging and/or curative care.
- Addressing racial and income disparities as well as other health disparities within palliative care.
- Process and patient outcome metrics.
- Addressing barriers to integrating recommendations into current care systems.
- Identifying other areas of focus or modifying areas, as needed.

Duties & Functions

The Palliative Care workgroup will:

- Research evidence-based and expert-opinion informed guidelines and best practices (emerging and established).
- Consult relevant professional associations and other stakeholder organizations and subject matter experts for feedback, as appropriate.
- Meet for approximately nine months, as needed.
- Provide updates at Bree Collaborative meetings.

¹ National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. www.nationalcoalitionhpc.org/ncp.

² Gomes B, Calanzani N, Curiale V, McCrone P, Higginson I. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Sao Paulo Med J*. 2016 Jan-Feb;134(1):93-4.

³ Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. *Cochrane Database Syst Rev*. 2011 Mar 16;(3):CD007132.

⁴ Haun MW, Estel S, Rücker G, Friederich HC, Villalobos M, Thomas M, et al. Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev*. 2017 Jun 12;6:CD011129.

Bree Collaborative Palliative Care Workgroup DRAFT

Updated: September 19, 2019

- Post draft report(s) on the Bree Collaborative website for public comment prior to sending report to the Bree Collaborative for approval and adoption.
- Present findings and recommendations in a report.
- Recommend data-driven and practical implementation strategies.
- Create and oversee subsequent subgroups to help carry out the work, as needed.
- Revise this charter as necessary based on scope of work.

Structure

The workgroup will consist of individuals confirmed by Bree Collaborative members or appointed by the chair of the Bree Collaborative or the workgroup chair. The chair of the workgroup will be appointed by the chair of the Bree Collaborative. The Bree Collaborative program director and program assistant will staff and provide management and support services for the workgroup.

Less than the full workgroup may convene to: gather and discuss information; conduct research; analyze relevant issues and facts; or draft recommendations for the deliberation of the full workgroup. A quorum shall be a simple majority and shall be required to accept and approve recommendations to send to the Bree Collaborative.

Meetings

The workgroup will hold meetings as necessary. The program director will conduct meetings along with the chair, arrange for the recording of each meeting, and distribute meeting agendas and other materials prior to each meeting. Additional workgroup members may be added at the discretion of the workgroup chair.

Name	Title	Organization
John Robinson, MD, SM (Chair)	Chief Medical Officer	First Choice Health
Lydia Bartholomew, MD	Senior Medical Director, Pacific Northwest	Aetna
George Birchfield, MD	Inpatient Hospice	EvergreenHealth
Raleigh Bowden, MD	Director	Okanogan Palliative Care Team
Mary Catlin, MPH	Senior Director	Honoring Choices, Washington State Hospital Association
Randy Curtis, MD, MPH	Director, Cambia Palliative Care Center of Excellence	University of Washington Medicine
Leslie Emerick	Director of Public Policy	Washington State Hospice and Palliative Care Organization
Ross Hayes, MD	Palliative Care Program, Bioethics, Rehabilitation, Pediatrician	Seattle Childrens
Greg Malone, MA, MDiv, BCC	Palliative Care Services Manager	Swedish Medical Group
Kerry Schaefer, MS	Strategic Planner for Employee Health	King County
Bruce Smith, MD	Medical Director of Providence Hospice of Seattle	Providence Health and Services
Richard Stuart, DSW	Psychologist	Swedish Medical Center - Edmonds Campus
Stephen Thielke, MD	Geriatric Psychiatry	University of Washington
Cynthia Tomik, LICSW	Manager, Palliative Care	EvergreenHealth
Gregg Vandekieft, MD, MA	Medical Director for Palliative Care	Providence St. Peter Hospital
Hope Wechkin, MD	Medical Director, Hospice and Palliative Care	EvergreenHealth

Appendix C: Guideline and Systematic Review Search Results

	Year	Title	Summary
AHRQ: Research Findings and Reports	2017	Assessment Tools for Palliative Care	We identified more than 150 assessment tools addressing most domains of palliative care, but few tools addressed the spiritual, structure and process, ethical and legal, or cultural domains, or the patient-reported experience subdomain. While some data on the psychometric properties of tools exist, the responsiveness of different tools to change has largely not been evaluated. Future research should focus on: (1) developing or testing tools in palliative care populations for domains with few or no tools, (2) evaluating responsiveness of tools for all domains, and (3) further studying the use of palliative care tools in clinical care and as quality indicators.
	2016	Home-Based Primary Care Interventions	The services included in the HBPC interventions varied widely, and no identifiable combination was related to more positive outcomes. We identified four studies that evaluated the addition of specific services. Combining palliative care and primary care home visits increased the likelihood of death at home (2 studies; low strength of evidence), while studies on adding caregiver support (1 study) or transitional care (1 study) to HBPC were rated as having insufficient evidence.
	2014	Decision Aids for Advance Care Planning	Numerous decision aids are widely available but not represented in the empirical literature. Of the 16 published studies testing decision aids as interventions for adult ACP, most were proprietary or not openly available to the public. Decision aids tend to be constructed for the general population or for disease-specific conditions for narrower decision choices. Designing decision aids that are responsive to diverse philosophical perspectives and flexible to change as people gain experience with their personal illness courses remains an important concern. Future directions for effort include further research, training of ACP facilitators, dissemination and access, and the potential opportunities that lie in social media or other technologies.
	2012	Closing the Quality Gap Series: Improving Health Care and Palliative Care for Advanced and Serious Illness	We found that evidence was strongest (moderate strength of evidence) for interventions for pain, and for the targets of communication and decision making and continuity for selected outcomes. While a few high- and medium-quality, well-designed health care and palliative care interventions have been conducted to improve outcomes for patients with advanced and serious illness, this report highlights the continued presence of variable findings, quality deficiencies, vaguely defined interventions, and variable outcome measurement tools and reporting in much of this intervention literature. The evidence has a number of gaps, including few studies in the hospice setting or pediatrics.
	2010	A Review of Quality of Care Evaluation	Systematic reviews identified only 3 existing quality measurement sets that included quality measures for dyspnea care. The existing dyspnea quality measures reported by retrospective evaluations of care assess

	for the Palliation of Dyspnea	only 4 aspects: dyspnea assessment within 48 hours of hospital admission, use of objective scales to rate dyspnea severity, identification of management plans, and evidence of dyspnea reduction...The panel recommended that dyspnea assessment should include a measure of intensity and some inquiry into the associated bother or distress experienced by the patient. A simple question into the presence or absence of dyspnea would be unlikely to help guide therapy, as complete relief of dyspnea in advanced disease would not be anticipated.
2010	A Framework for Assessing Quality Indicators for Cancer Care at the End-of-Life	The framework describes five steps for developing and assessing a quality indicator for end-of-life care, defining the (1) population of focus; (2) broad quality domains; (3) specific target areas; (4) steps of the care process; and (5) evaluation criteria for quality indicators. The defined population includes seriously or terminally ill cancer patients, who are unlikely to recover or stabilize, and their families. Domains include the structure and processes of care; physical, psychiatric, psychosocial, spiritual, and cultural aspects of care; as well as the care of the imminently dying, ethical legal issues, and the delivery of care. Evaluation criteria include importance; scientific acceptability, including validity, evidence to improve outcomes, reliability, responsiveness, and variability; usability; and feasibility, including ready data sources.
2010	Cancer Quality-ASSIST Supportive Oncology Quality Indicator Set: Feasibility, Reliability, and Validity Testing	We successfully evaluated 78 indicators across the domains; results were similar in the two settings. We could not feasibly evaluate 3 indicators because of low prevalence; 22 indicators had significant interrater reliability issues, 9 had significant validity issues, and 3 had both reliability and validity issues, leaving a set of 41 indicators most promising for further testing and use in this population, with an overall kappa score of 0.85 for specified care.
Cochrane Collection	2017 Early palliative care for adults with advanced cancer	This systematic review of a small number of trials indicates that early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although we found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common. At this point, effects on mortality and depression are uncertain. We have to interpret current results with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods. Additional research now under way will present a clearer picture of the effect and specific indication of early palliative care. Upcoming results from several ongoing studies (N = 20) and studies awaiting assessment (N = 10) may increase the certainty of study results and may lead to improved decision making. In perspective, early palliative care is a newly emerging field, and well-conducted studies are needed to explicitly describe the

		components of early palliative care and control treatments, after blinding of participants and outcome assessors, and to report on possible adverse events.
2017	Psychosocial interventions for fatigue during cancer treatment with palliative intent	We found little evidence around the benefits of psychosocial interventions provided to reduce fatigue in adult patients with incurable cancer receiving cancer treatment with palliative intent. Additional studies with larger samples are required to assess whether psychosocial interventions are beneficial for addressing fatigue in patients with incurable cancer.
2016	Palliative care interventions in advanced dementia	Very little high quality work has been completed exploring palliative care interventions in advanced dementia. There were only two included studies in this review, with variation in the interventions and in the settings that made it impossible to conduct a meta-analysis of data for any outcome. Thus, we conclude that there is insufficient evidence to assess the effect of palliative care interventions in advanced dementia. The fact that there are six ongoing studies at the time of this review indicates an increased interest in this area by researchers, which is welcome and needed.
2015	Training and supportive programs for palliative care volunteers in community settings	The use of palliative care volunteers is likely to continue, but there is an absence of evidence to show how best to train or support them whilst maintaining standards of care for palliative care patients and their families.
2015	Psychological therapies for sickle cell disease and pain	Evidence for the efficacy of psychological therapies in sickle cell disease is currently limited. This systematic review has clearly identified the need for well-designed, adequately-powered, multicentre randomised controlled trials assessing the effectiveness of specific interventions in sickle cell disease.
2013	Effectiveness and cost-effectiveness of home palliative care services for adults with	The results provide clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.

	advanced illness and their caregivers	
2012	Spiritual and religious interventions for well-being of adults in the terminal phase of disease	We found inconclusive evidence that interventions with spiritual or religious components for adults in the terminal phase of a disease may or may not enhance well-being. Such interventions are under-evaluated. All five studies identified were undertaken in the same country, and in the multi-disciplinary palliative care interventions it is unclear if all participants received support from a chaplain or a spiritual counsellor. Moreover, it is unclear in all the studies whether the participants in the comparative groups received spiritual or religious support, or both, as part of routine care or from elsewhere. The paucity of quality research indicates a need for more rigorous studies.
2011	Interventions for improving palliative care for older people living in nursing care homes	We found few studies, and all were in the USA. Although the results are potentially promising, high quality trials of palliative care service delivery interventions which assess outcomes for residents are needed, particularly outside the USA. These should focus on measuring standard outcomes, assessing cost-effectiveness, and reducing bias.
2011	Non-invasive interventions for improving well-being and quality of life in patients with lung cancer	Nurse follow-up programmes and interventions to manage breathlessness may produce beneficial effects. Counselling may help patients cope more effectively with emotional symptoms, but the evidence is not conclusive. Other psychotherapeutic, psychosocial and educational interventions can play some role in improving patients' quality of life. Exercise programmes and nutritional interventions have not shown relevant and lasting improvements of quality of life. Reflexology may have some beneficial effects in the short term.
2009	Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease	In the absence of randomised controlled trials or controlled clinical trials, the 'best' evidence to date is based on three 'low' and two 'very low quality' observational studies. These suggest 'very low quality evidence' for an advantage for mental health domains (only) of quality of life without increasing healthcare costs, and 'low level quality' evidence for reduced hospitalisation for MDC in low-intensity outpatient settings; and 'very low quality' evidence for improved disability in high-intensity settings. The evidence for survival is conflicting. These conclusions are tentative and the gap in current research should not be interpreted as proof that MDC is ineffective. Further research is needed into appropriate study designs; outcome measurement; caregiver needs; and the evaluation of optimal settings, type, intensity or frequency and cost-effectiveness of MDC in the MND population. Future research should focus on observational designs to assess care and outcomes in 'real-life' settings. The interface between neurology, rehabilitation and palliative care should be explored to provide long-term support for MND.

<i>Health Technology Assessment Program</i>	None		
<i>Centers for Disease Control and Prevention</i>	Nothing specific, 2016 Opioid Prescribing Guidelines for Chronic Pain		
<i>Institute for Clinical and Economic Review</i>	<u>2016</u>	Palliative Care in the Outpatient Setting	Overall, the evidence describing outpatient palliative care's benefit is stronger for QoL, resource utilization outcomes, patient satisfaction, and mood outcomes, with more limited evidence suggesting benefits on survival, symptom burden, psychosocial, and caregiver outcomes. These observations are consistent with the fact that outpatient palliative care programs are designed to increase patient social support, patient self-advocacy, and coordinated medical care; while palliative care is not focused on improved survival as an indicator of effectiveness, the survival benefit may be mediated by the other more directly influenced outcomes of interest (e.g., mood, QoL).
<i>Veterans Administration Evidence-based Synthesis Program</i>	<u>2017</u>	Integrated Outpatient Palliative Care in Oncology	With the increase in availability of clinical palliative care services, organizations have tested and implemented varying degrees and types of integration with oncology care. These can be evaluated using common instruments, like the Integrated Practice Assessment Tool based on the health care integration framework by Heath et al. Adapted from this framework, levels of integration across palliative care and oncology have recently been proposed in the Collaborative Care Continuum framework by Kaufmann et al. In addition to levels of integration, leaders have described various methods of integration of services, including co-rounding models for hospitalized patients, embedded or co-located outpatient clinical services, and standalone clinics or services. Further, organizations have had positive experiences with integrated services limited to particular disease or conditions, types of therapy (eg, investigational agents or novel immunotherapy drugs), or by embedding palliative care experts into non-patient-facing case discussions such as multidisciplinary oncology team meetings ("tumor boards"). In addition to other types of integration, much focus has been on the outpatient setting, which is where the majority of cancer care is delivered. For palliative care, the outpatient realm has been considered the "next frontier" of community-based palliative care services, and although growth is robust, many communities do not have access to non-hospital services.

*National
Consensus
Project for
Quality
Palliative Care
National
Coalition for
Hospice and
Palliative Care*

2018

[Clinical Practice
Guidelines for
Quality Palliative
Care, 4th edition](#)

The NCP Guidelines, 4th edition, are organized into 8 domains:

Domain 1: Structure and Processes of Care The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Domain 1 also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.

Domain 2: Physical Aspects of Care The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.

Domain 3: Psychological and Psychiatric Aspects The domain focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.

Domain 4: Social Aspects of Care Domain 4 outlines the palliative care approach to assessing and addressing patient and family social support needs.

Domain 5: Spiritual, Religious, and Existential Aspects of Care The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.

Domain 6: Cultural Aspects of Care The domain outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.

Domain 7: Care of the Patient Nearing the End of Life This domain focuses on the symptoms and situations that are common in the final days and weeks of life.

Domain 8: Ethical and Legal Aspects of Care Content includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.

Appendix D: Defined Patient Population

Payment Reforms to Improve Care for Patients with Serious Illness Patient and Caregiver Support for Serious Illness (PACSSI)

The American Academy of Hospice and Palliative Medicine that developed the Payment Reforms to Improve Care for Patients with Serious Illness Patient and Caregiver Support for Serious Illness (PACSSI) bundled payment model including defining a serious illness population as follows (including criteria from all three categories):

PACSSI Eligibility and Tiering Criteria

Tier	Diagnosis of Serious Illness (one of the below) AND	Function (one of the below) AND	Health Care Utilization
Tier 1: Moderate Complexity	One of the specified diseases, disorders, or health conditions in Table 2 below Three or more serious chronic conditions*	Non-Cancer: PPS of $\leq 60\%$ or ≥ 1 ADLs or DME order (oxygen, wheelchair, hospital bed) Cancer: PPS of $\leq 70\%$ or ECOG ≥ 2 or ≥ 1 ADL or DME order (oxygen, wheelchair, hospital bed)	One significant health care utilization in the past 12 months, which may include: - ED visit - Observation stay - Inpatient hospitalization Note: This criterion may be waived under certain circumstances specified below.
Tier 2: High Complexity	Same as above, Excluding dementia as the primary illness	Non-Cancer: PPS of $\leq 50\%$ or ≥ 2 ADLs Cancer: PPS of $\leq 60\%$ or ECOG ≥ 3 or ≥ 2 ADLs	Inpatient hospitalization in the past 12 months AND one of the following - ED visit - Observation stay - Second Hospitalization Note: This criterion may be waived under certain circumstances specified below.

Diagnoses

Option 1: A diagnosis of one of the following would meet the serious illness criterion:

- Metastatic Cancer
- Pancreatic, Gastrointestinal, Lung, Brain, Hematologic, or Ovarian cancers
- Heart Failure with Class III or IV level function under the New York Heart Association (NYHA) Functional Classification
- Heart Failure with a Left Ventricular Assist Device (LVAD)
- Advanced Pulmonary Disease (Pulmonary Hypertension, Chronic Obstructive Pulmonary Disease, Pulmonary Fibrosis)
- Advanced Dementia with stage 6 or 7 using the Functional Assessment Staging Tool (FAST) or ≥ 2 ADLs*
- Progressive Neurologic Disorder (e.g. Cerebrovascular Accident (CVA), Parkinson's Disease, Amyotrophic Lateral Sclerosis, Progressive Supranuclear Palsy)
- Hepatic Failure (Cirrhosis)
- Stage IV or V Renal Disease
- Protein-Calorie Malnutrition
- Cachexia
- Hip Fracture (with functional decline)

Option 2 Diagnoses of three or more serious chronic conditions would also allow a patient to meet the serious illness criterion.

* Dementia as the primary illness would be confined to the moderate complexity group, as the rate of decline is often slow, and functional limitations occur significantly earlier in the course of an illness.

Washington State Rural Palliative Care Initiative Palliative Care Screening Tool

Patient Name: _____ Date: _____

(Not a permanent part of the medical record)

Criteria – Please consider the following criteria when determining the palliative care score of this patient			
SECTION 1-BASIC CONDITION		<input type="checkbox"/> Late stage dementia (decreased verbalization/ambulation) <input type="checkbox"/> Advanced cardiac disease – i.e. CHF severe CED, CM (LVEF < 25%) <input type="checkbox"/> Other life-limiting condition	SCORING Score 2 Points Each _____
<input type="checkbox"/> Cancer (Metastatic/Recurrent) <input type="checkbox"/> Advanced COPD (SOB in conversation or at rest/continuous O ₂) <input type="checkbox"/> Stroke (with decreased function by at least 50%) <input type="checkbox"/> End stage renal disease (Stage 4)			
If the score for Section 1 above is zero the patient does not meet the basic definition of seriously ill. STOP HERE IF SCORE IS 0 FOR SECTION ONE			
SECTION 2-COMORBIDITY CONDITIONS		<input type="checkbox"/> Moderate congestive heart failure <input type="checkbox"/> Other condition complicating cure <input type="checkbox"/> Early to mid-stage dementia	Score 1 Point Overall _____
<input type="checkbox"/> Liver disease <input type="checkbox"/> Moderate renal disease <input type="checkbox"/> Moderate COPD			
SECTION 3 FUNCTIONAL STATUS OF PATIENT			Score as specified below
Using ECOG Performance Stratus (Eastern Cooperative Oncology Group)			
ECOG Grades	Fully Active, able to carry on all pre-disease activities without restriction.	Score 0	ECOG score _____
0			
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.	Score 1	
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.	Score 2	
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours	Score 3	
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.	Score 4	
SECTION 4 OTHER CRITERIA TO INCLUDE IN SCREENING			Score 1 point EACH
Unacceptable level of pain or other uncontrolled symptoms			_____
Unresolved psychosocial or spiritual issues			_____
Frequent visits to the Emergency Department and or hospital admissions			_____
Prolonged hospital stays			_____
Family/caregiver limitations or lack of consensus related to planning or prognosis			_____
Lacks advanced directive and or identified healthcare agent			_____
Other complex situations or significant limitations			_____
TOTAL SCORE			_____
SCORING GUIDELINES	Scoring schema inserted by organization		

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