3 / Patient and Family/caregiver-Centered Care (PFC)
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PRINCIPLES

• Providing care and services that are focused on the dying person and the grieving family’s unique experience.
• The patient, family, caregiver, and other individuals identified by the patient are the unit of care.
• The hospice interdisciplinary team, in partnership with the patient, family, caregiver, and other individuals identified by the patient, develops, coordinates, and implements a care-directed, individualized, and safe plan of palliative care.
• Addressing grief and bereavement needs begins at the time of admission to hospice with the initial comprehensive assessment and continues through 13 months after the patient’s death, and beyond if necessary.
• Anticipatory grief services are provided to help patients, families, caregivers, and other individuals identified by the patient cope with the losses that occur during the illness and eventual death. Bereavement services are provided prior to and after death based on a plan of care that is created from a thorough bereavement assessment, including risk factors for complicated grief, social support, concurrent life stressors, relationship with the deceased, and other relevant factors.

Standard:

PFC 1: Hospice services are available twenty-four (24) hours a day, seven (7) days a week.

PFC 1.1 The hospice assures a timely response to patient and family/caregiver/caregiver telephone calls twenty-four (24) hours a day, seven (7) days a week.

PFC 1.2 Professional staff is available to make visits to address patient and family/caregiver/caregiver needs twenty-four (24) hours a day, seven (7) days a week.

PFC 1.3 Hospice interdisciplinary team support is accessible and available twenty-four (24) hours a day, seven (7) days a week.

PFC 1.4 Professional staff consultation and visits provide assessment, instruction, support, and interventions, as needed.
PFC 1.5 The hospice has reporting mechanisms and procedures to ensure that staff and volunteers are regularly informed and updated on the patient’s current status after regular business hours.

Practice Examples:

- A system is in place to respond to contacts and meet patient and family/caregiver needs after regular business hours.
- Patients and families receive written information at the time of admission regarding how and when to access care after regular business hours. All team members regularly reinforce this information throughout the course of care.
- An established means of staff communication (e.g., written, electronic, voicemail) exists to assure the accurate and timely transmission of information on a daily basis.
- The hospice has an established method to relay documentation of actions taken after regular business hours (e.g. protected/encrypted emails and texts, faxes, documentation in the patient (electronic) medical record). On-call logs are used to document the response to all contacts and requests made after regular business hours.
- The hospice interdisciplinary team creates recommendations, parameters for interventions, and updates for staff providing care to patients and families/caregivers after regular business hours to ensure continuity of care. The updates include new or changed medications, changes in the patient’s condition, a summary of current issues, individualized approaches, special concerns, and information on uncommon diagnoses.
- Policies and procedures have been established to ensure all levels of care are provided as needed and can be initiated twenty-four (24) hours a day.

Standard:

**PFC 2: Care is fully coordinated to assure ongoing continuity for the patient, family, and caregiver(s).**

PFC 2.1 The hospice has criteria and a written process for receiving referrals and verification of eligibility which is used to make admission decisions for both adult and pediatric patients.

PFC 2.2 Procedures are established and utilized for initial and ongoing assessment of patients and families by all disciplines, including processes to evaluate special needs of children and Veterans, based on regulatory and hospice-defined time frames.

PFC 2.3 The hospice has criteria for determining appropriate levels of care, supports the decision of level of care with documentation, and utilizes all levels of care based on patient and family/caregiver needs.

PFC 2.4 The clinical record contains documentation of care coordination through documentation of all hospice interdisciplinary team contact including conference meetings, telephone communication, after-hours contacts and actions, and the visits by hospice interdisciplinary team members.
PFC 2.5 The hospice team delineates a process to transition family members and caregivers from patient care to bereavement care.

PFC 2.6 Documentation supports the patient’s continuing terminal prognosis and eligibility.

PFC 2.7 The hospice team coordinates care with non-hospice healthcare providers, resource providers, and vendors involved in the patient’s care (e.g., community health programs, healthcare facilities, nursing homes, pharmacists, health insurance programs, physical therapists, specialist physicians, nurse practitioners and physician assistants (effective 1-1-2019)).

Practice Examples:

- The attending physician is informed of pertinent and significant changes related to the patient’s condition and the plan of care.
- Hospice interdisciplinary team meetings include contracted service providers, spiritual counselors, attending physicians (if any), volunteers, bereavement counselors, and family/caregivers or representative when needed to address issues related to the coordination of care.
- The registered nurse who performs the initial nursing assessment will discuss and review the medical history, terminal and related diagnoses, unrelated diagnoses, medication review, and the plan of care with the hospice physician.
- Grief and bereavement needs are identified and addressed at the time of admission and throughout the episode of care. A plan for bereavement care following the death is created and addresses any survivor risk factors identified at the time of the bereavement assessment.
- Processes are established to determine which medications are related and unrelated to the terminal prognosis and contributing conditions and diagnoses. Responsibility for payment is considered by the hospice for medications related to the terminal prognosis. Provision of medications is coordinated with health plans and pharmacies to ensure timely decision making and pharmacy service delivery.
- Processes are established in nursing facilities for the coordination of hospice care and services provided to hospice-enrolled nursing facility residents, with facility staff, the facility health care team, and the hospice interdisciplinary team.
  - The nursing facility plan of care is integrated with the hospice plan of care and reflects collaborative efforts to address the care needs of the nursing facility resident enrolled in hospice and family/caregivers or representative.
  - The hospice and the nursing facility develop a plan for communication about patient needs and changes.
Standard:

PFC 3: The hospice designates a hospice interdisciplinary team that assesses need and plans, directs, coordinates, and evaluates effectiveness of care and services provided to the patient, family/caregiver, and other family members.

PFC 3.1 The hospice interdisciplinary team must include:

1. Hospice physician;
2. Registered nurse;
3. Social worker; and
4. Pastoral or spiritual counselor.

Additional hospice interdisciplinary team members may include:

1. Patient’s attending physician (if any);
2. Other physicians involved in the patient’s care;
3. Nurse practitioner;
4. Physician assistant;
5. Pharmacist;
4. Volunteer;
5. Bereavement counselor;
6. Hospice aide;
7. Physical therapist, occupational therapist, speech-language pathologist and/or dietary counselor; and
8. Other clinicians, counselors, or healthcare practitioners involved in the patient’s care.

Practice Examples:

• Attending physicians (if any) are invited to attend hospice interdisciplinary team meetings when their patients’ care plans are scheduled for review and updating.
• Volunteers, bereavement counselors, physical therapists, occupational therapists, speech-language pathologists, dietary counselors, and volunteer managers/coordinators who provide patient support/care are invited to provide input, attend the hospice interdisciplinary team meetings, and participate in discussions regarding their assigned patients.
• Staff members who serve in more than one capacity (e.g., spiritual care and bereavement) will maintain awareness of their respective professional roles to ensure healthy boundaries and clear communication in patient and family/caregiver/caregiver relationships.
• Nursing facility staff members are invited to attend the hospice interdisciplinary team meetings when care plans for residents who are hospice patients at their facilities are scheduled for review and updating.
Standard:

**PFC 4:** A written individualized plan of care is developed by the hospice registered nurse in collaboration with the other members of the hospice interdisciplinary team. The care plan is based on information gathered from clinical information about the patient as well as the initial nursing assessment, and reflects the needs of the patient and family/caregiver, and addresses care and services to be provided.

**PFC 4.1** Comprehensive assessments are completed to accurately reflect the patient’s physical, psychosocial, emotional, and spiritual needs. The plan of care is based on comprehensive interdisciplinary assessments that include evaluation of physical, psychological, emotional, spiritual, medication, and equipment needs, including but not limited to:

1. Patient and family/caregiver goals for care;
2. Principal and secondary diagnoses and any co-morbid conditions;
3. Current medical findings, including clinical features and complications, that support the terminal prognosis;
4. Patient’s health status, including changes related to their terminal prognosis, symptoms, functional status, coping ability, and spiritual/existential concerns;
5. Family caregiver’s functional and cognitive capacity, coping ability, anticipatory grieving, preparation for the death, and spiritual needs;
6. Patient’s and family’s social support, cultural, and resource needs; and
7. Special population needs of patient and family/caregiver, such as Veteran, children, disability, etc.

**PFC 4.2** The plan of care includes strategies and planned interventions for addressing needs identified through assessment (e.g., the management of pain, symptoms, and psychosocial or spiritual concerns) as well as frequency of contact by the hospice interdisciplinary team. The plan of care consists of but is not limited to:

1. Patient and family/caregiver preferences and desired outcomes;
2. Patient’s and family caregiver’s needs;
3. Interventions directed to achievement of desired outcomes and meeting the needs of the patient and family/caregiver as identified by the hospice interdisciplinary team;
4. Scope, frequency, and type of services to be provided, including hospice interdisciplinary team interventions;
5. Medications, medical equipment, and supplies necessary to meet the needs of the patient; and
6. Agencies or organizations, healthcare providers, or services that may be involved in the care.

**PFC 4.3** The patient and family/caregiver are routinely engaged in developing the plan of care in a language and manner that they can understand. They are informed about options for care and may participate in planning, care, and treatment.

**PFC 4.4** The hospice documents patient and family/caregiver participation, understanding, and level of agreement with the plan of care.
Practice Examples:

- The initial assessment visit is completed by the hospice registered nurse. Other hospice interdisciplinary team members, such as the social worker, may accompany the nurse.
- The plan of care is developed, based on assessments by the hospice interdisciplinary team members, with the patient, family/caregiver, hospice medical director, and attending physician (if any). The plan of care is reviewed and updated at least every 15 days or more frequently as indicated by changes in the patient’s condition or family circumstances.
- The hospice uses a military history checklist to evaluate the impact of military experience on care needs and to determine if there are benefits to which the Veteran and surviving dependents may be entitled. Needs identified through use of the checklist are reflected in the plan of care.
- The plan of care is documented and communicated to all hospice interdisciplinary team members involved in providing care and services to the patient and family/caregiver.
- If the patient or family/caregiver has limited English speaking proficiency or other special communication needs, an approach to communication is developed and is indicated in the plan of care (e.g., use of a language line translation service, TTY for the deaf). Note that translation by a family member should be used as a last resort, or at the patient’s specific request.

Standard:

**PFC 5: The hospice interdisciplinary team members implement the interventions identified in the plan of care.**

PFC 5.1 The hospice interdisciplinary team members provide services according to the scope and frequency specified in the plan of care.

PFC 5.2 The hospice interdisciplinary team members’ interventions are directed toward achieving the desired goals or outcomes in the plan of care.

PFC 5.3 Each hospice interdisciplinary team member documents and communicates the interventions performed with the patient and family/caregiver, their response to care and services provided, and the goals or outcomes achieved.

Practice Examples:

- The clinical record reflects that the frequency of visits by the hospice interdisciplinary team members is in accordance with the visit frequency stated in the plan of care.
- Documentation in the patient record by each hospice interdisciplinary team member reflects and is consistent with the interventions related to the specific goals of care identified in the plan of care.
• During interdisciplinary meetings, team members discuss the interventions and plan for the patient’s care.

**Standard:**

*PFC 6: The hospice interdisciplinary team reviews, revises, and documents the plan of care to reflect the specific and changing needs of the patient and family/caregiver.*

PFC 6.1 The plan of care is reviewed, revised, and documented in the patient’s clinical record by the hospice interdisciplinary team at least every 15 calendar days.

PFC 6.2 Reassessment is performed during any contact by hospice interdisciplinary team members with the patient and/or family/caregiver.

PFC 6.3 The hospice interdisciplinary team revises the plan of care on an ongoing basis in response to changes in the status and care needs of the patient and the family/caregiver.

PFC 6.4 Hospice interdisciplinary team meeting documentation reflects the ongoing assessment of the patient’s and family’s needs and their participation in and agreement with the development and revision of the plan of care.

**Practice Examples:**

• The patient’s and family’s needs are reassessed during each visit by hospice interdisciplinary team members and documented in the patient record.

• Significant information obtained during patient and family/caregiver reassessment that is relevant to the plan of care is immediately communicated with other hospice interdisciplinary team members, documented in the clinical record, and the plan of care is collaboratively revised accordingly.

• For facility residents who are enrolled in hospice, documentation in the patient record demonstrates collaboration and communication by hospice team members and facility staff, and the plan of care is revised in response to the patient and family/caregiver reassessment.

• The nursing facility plan of care is integrated with the hospice plan of care and reflects collaborative efforts to address the care needs of the hospice enrolled nursing facility resident, the family representative, and facility staff.

**Standard:**

*PFC 7: A registered nurse coordinates the delivery of care provided by the hospice interdisciplinary team of professionals and volunteers to assure that the patient’s and family’s needs are continuously assessed, planned for, and addressed.*
PFC 7.1 The hospice registered nurse coordinates care while taking into consideration the patient’s and family’s needs and strengths and the health professionals involved in the care.

PFC 7.2 The hospice registered nurse’s responsibilities include:

1. Coordinating the hospice interdisciplinary team to ensure adequate assessment, planning, and implementation of each patient’s and family’s plan of care; and
2. Ensuring effective hospice interdisciplinary team practice, coordination, and communication among team members.

Practice Examples:

- The hospice has a written job description for the registered nurse that outline qualifications and responsibilities as case manager.
- Care coordination by the nurse case manager among hospice interdisciplinary team members and across care settings is observable through a review of hospice interdisciplinary team conference notes, telephone communication, and clinical visit notes in the clinical record.

Standard:

**PFC 8: The hospice interdisciplinary team identifies a patient’s values, spiritual beliefs, and/or philosophies and honors these perspectives in all care coordination and planning.**

PFC 8.1 A spiritual assessment is completed as part of the comprehensive assessment and spiritual support is provided according to the patient and family/caregiver’s preferences and needs.

PFC 8.2 The hospice interdisciplinary team recognizes feelings and concerns such as loneliness, guilt, fear, and anger which may be shared by the patient and family/caregiver and addresses these according to patient and family/caregiver preferences.

PFC 8.3 The hospice interdisciplinary team assesses individual and family culture, history, and dynamics and utilizes the assessment as the basis for understanding and supporting patient’s and family’s wishes and developing appropriate interventions.

Practice Examples:

- Procedures and protocols are in place for including the patient’s spiritual support system, as defined by the patient, in the care planning process.
- A spiritual assessment that addresses spiritual issues and concerns is completed within five days of electing hospice care.
- Documentation in the patient record indicates that the patient’s spiritual beliefs and traditions are communicated to and supported by the hospice interdisciplinary team.
• All staff receives training to ensure an understanding of the ethical boundaries prohibiting the imposition of one's own beliefs on the patient or family.

**Standard:**

**PFC 9: The hospice interdisciplinary team promotes opportunities for integration, reconciliation, and closure according to the preference of the patient.**

PFC 9.1 The hospice interdisciplinary team helps the patient to identify areas of importance in achieving integration, reconciliation, and end-of-life closure including self, family, friends, and community.

PFC 9.2 The patient's strengths and unique qualities are supported by hospice interdisciplinary team members.

PFC 9.3 Additional support is offered and provided according to the patient’s preferences as the patient approaches death.

PFC 9.4 Cultural perspectives and beliefs on death are recognized, honored, and supported in ways that are meaningful to the patient and family/caregiver.

**Practice Examples:**

• The hospice has written materials that explain what to expect during the dying process for the patient and family/caregiver (e.g., signs and symptoms of approaching death) in a manner and language that each understands.

• The hospice develops specially trained volunteer programs to provide patient and family/caregiver support, such as a vigil program, as death approaches.

• At the patient’s request, the hospice chaplain or designated spiritual care coordinator facilitates patient contact with a faith community when the patient has been inactive for some time due to the progression of the patient’s illness.

• At the patient’s request, hospice staff may seek to facilitate visits for special needs, such as immigration problems or incarceration issues.

• Following the death, the hospice interdisciplinary team provides care of the body, honors cultural rituals when possible, and assists the family with funeral arrangements as needed.

**Standard:**

**PFC 10: The patient’s ability for self-care is regularly assessed and interventions are implemented in accordance with patient and family/caregiver wishes when the patient is no longer able to adequately provide self-care.**
PFC 10.1 Medical equipment and supplies are provided to assist in the care of the patient as indicated.

PFC 10.2 Policies and procedures are developed to plan for patient care when there is no primary caregiver in the patient’s residence.

PFC 10.3 Communication strengths and barriers (e.g., cognitive deficits, lack of proficiency in English) are routinely assessed and appropriate actions are taken to ensure patient understanding of care.

PFC 10.4 When indicated, a coordinated transition to another setting is facilitated by the hospice interdisciplinary team in order to meet the patient’s care needs.

**Practice Examples:**

- The hospice ensures that non-English speaking patients and their families have access to information in an understandable form by offering literature written in languages for non-English speaking communities common in the hospice’s service area and access to translators twenty-four (24) hours a day, seven (7) days a week.
- Assisted devices are available to the deaf and hearing impaired through local community TTY service providers.
- The hospice has appropriate procedures in place to support education and communication with those who have a limited ability to read and/or write and, when creating written materials, is mindful that much of the general population reads on a fifth grade level.
- Hospice staff proactively works with patients and families in planning for a higher level or increased intensity of care as needed as the patient’s condition changes.
- The hospice helps the patient who lives alone to explore possible options for care when the patient can no longer care for himself/herself, such as a nursing facility, a hospice residence, a family member’s home, or paid or unpaid assistants in the home.

**Standard:**

**PFC 11: The family’s ability to emotionally and/or spiritually adjust to changing conditions is assessed as a part of the ongoing comprehensive psychosocial and spiritual assessment.**

PFC 11.1 The care planning process includes interventions that address the needs and goals of the family related to end-of-life care, loss, and grief.

PFC 11.2 Family members’ spiritual beliefs, traditions, and rituals are respected during the care planning process.

PFC 11.3 Family members’ feelings of loss, despair, loneliness, unresolved guilt, fear, and anger are recognized and addressed by the hospice interdisciplinary team.
PFC 11.4 Appropriate and timely communication and education are provided to the patient and family/caregiver from admission to discharge or death, and through bereavement.

Practice Examples:

- Psychosocial assessment tools include assessment of family history and coping skills.
- Family discord is identified and addressed in the plan of care as it relates to or impacts patient wellbeing and care needs.
- Bereavement staff routinely attends hospice interdisciplinary team meetings and participates in the care planning process.
- The hospice interdisciplinary team counsels patients and families who cannot take leave from work after the patient is diagnosed with a terminal illness.
- A hospice counselor meets with the caregiver to assist with unresolved grief issues from the past and anticipatory grief.
- The hospice interdisciplinary team respects and normalizes feelings of anger experienced by a young patient’s parents as they live with the reality of their child’s illness.
- The hospice interdisciplinary team counsels a patient and family/caregiver in dealing with issues of post-traumatic stress disorder or other disorders due to the patient’s military history and combat duty experience.
- The hospice bereavement counselor assists a patient’s spouse with coping with multiple recent family losses occurring over a short time span.
- The hospice interdisciplinary team educates the family on what to expect at the time of death and bereavement by using appropriate teaching tools.
- The hospice interdisciplinary team assists the patient’s same-sex partner in navigating legal and financial challenges related to decision-making for the patient.

Standard:

**PFC 12: The hospice interdisciplinary team promotes opportunities for reconciliation and end-of-life conversations according to patient and family/caregiver preference.**

**PFC 12.1** The hospice interdisciplinary team helps the patient and family/caregiver members identify important subject areas for reconciliation and end-of-life conversations.

**PFC 12.2** The hospice interdisciplinary team facilitates communication between the family members and the patient by encouraging expression of emotions related to grief and loss (love, concern, regret, gratitude, and forgiveness) as appropriate to the needs and desires of the patient and family/caregiver.

**PFC 12.3** Family members are educated about the physical, psychological, emotional, and spiritual aspects of the dying process.

**PFC 12.4** The hospice interdisciplinary team nurtures and supports a sense of meaning for family members related to their relationships with each other and the family’s identity within the community.
Practice Examples:

- Family members are encouraged to meet individually with the patient and express their feelings, facilitated by the hospice social worker and spiritual care coordinator or chaplain, if desired.
- Family members are educated about the patient’s possible withdrawal from others as death approaches and are supported as they continue to care for the patient.
- The hospice uses a reminiscence tool to help the patient and family/caregiver remember and appreciate their lives together (e.g., journals, CDs, photos), with possible utilization of expressive therapy.
- Family meetings are offered as needed and facilitated by the hospice interdisciplinary team to help resolve issues and make decisions related to the patient’s plan of care.

Standard:

**PFC 13: The hospice interdisciplinary team evaluates and supports the family’s physical, cognitive, and social capacity to communicate, learn, and carry out caregiving responsibilities.**

PFC 13.1 Patient care and physical safety are regularly evaluated and interventions to ensure safety are incorporated into the care planning process as needed.

PFC 13.2 The capability and willingness of caregivers to participate in the care of the patient are regularly evaluated and interventions for change or improvement are incorporated into the care planning process, as needed.

PFC 13.3 Cultural language barriers, disabilities, caregiver burden, and other factors that impact communication are recognized and interventions are developed to support learning and effective caregiving.

PFC 13.4 The hospice takes a proactive approach to medication safety with particular attention to opioid safety to ensure that all medications are used and stored safely. Examples of proactive approaches:

1. Conduct opioid risk assessment
2. Identify who will control medication administration
3. Provide opioid safety education

Practice Examples:

- At the patient’s request, the hospice nurse or other hospice interdisciplinary team members regularly communicate with family members/caregivers, including those residing outside the immediate community, to update them on the patient’s condition.
- Volunteers are assigned to provide support services to patients when a family member/caregiver needs coverage for a special circumstance.
• The hospice offers respite care to family members/caregivers to support patients in staying in their own homes as long as possible by easing caregiver burden.
• Interpreter services or other language and communication strategies are available and utilized as appropriate.
• The hospice plan of care reflects specific arrangements for reconciliation of opioids on every RN visit, safe medication storage and administration, and review of the safety plan with the patient and family/caregiver if risk of diversion is identified.
• The hospice interdisciplinary team engages in contractual agreements with the patient and family/caregiver regarding unresolved safety issues to ensure staff and patient safety (e.g., smoking with oxygen, multiple falls, lack of patient supervision, weapons, abusive/violent behavior).

**Standard:**

**PFC 14:** The hospice interdisciplinary team assesses the patient’s and family’s environmental and financial resources as they relate to the provision of patient care.

**PFC 14.1** Housing, welfare, caregiver burden, and safety issues (e.g., problems with shelter or inadequate financial resources) are identified. Interventions are initiated according to patient and family/caregiver preferences.

**PFC 14.2** Personal business and family welfare issues, such as funeral and memorial service arrangements or financial, legal, and other services, are identified and interventions are initiated according to patient and family/caregiver preferences.

**Practice Examples:**

• The hospice interdisciplinary team educates the family on the importance of self-care, provides or suggests opportunities for additional support, and arranges for respite care to reduce caregiver burden.
• The hospice interdisciplinary team assists family members with additional care options, including placement for the patient as needed, appropriate to their financial capability.
• The hospice interdisciplinary team assists the patient and family/caregiver in completing advance directives, POLST, Five Wishes and/or another advance care planning tool and educates the patient and family/caregiver on the meanings of these documents on an ongoing basis.
• The hospice interdisciplinary team assists families with funeral or memorial service arrangements, and the hospice spiritual care coordinator or chaplain helps plan and conduct services as requested.
• For patients without third party payer coverage who are unable to pay for medically necessary hospice care, the hospice interdisciplinary team offers the option to complete a financial needs assessment for agency or community-sponsored financial assistance and facilitates the completion of the assessment, if necessary.
Standard:

**PFC 15: Assessment of patient and family/caregiver feelings, strengths, goals, and needs related to loss, grief, and bereavement is performed. Interventions are developed based on the assessment and are incorporated into the interdisciplinary plan of care.**

PFC 15.1 The hospice interdisciplinary team works in partnership with the patient and family/caregiver to identify issues that may complicate life closure.

PFC 15.2 The hospice interdisciplinary team encourages, facilitates, and validates the patient’s and family’s expressions of grief related to losses identified by the patient and family/caregiver.

PFC 15.3 The hospice interdisciplinary team supports patients and families/caregivers in their grief process through direct services and by referrals to appropriate community resources for additional assistance if needed.

PFC 15.4 Survivor risk and bereavement assessment tools are utilized by the hospice from admission throughout the course of care and through thirteen (13) months after the death.

PFC 15.5 The hospice interdisciplinary team identifies, documents, and addresses the patient’s and family/caregiver’s needs and goals related to anticipatory grief (before death) and bereavement (following death).

PFC 15.6 The hospice interdisciplinary team documents the evaluation of bereavement needs, the hospice’s response to assessed needs, and the bereaved person’s response to services provided.

Practice Examples:

- A bereavement risk assessment is completed at start of care to identify risk factors for complicated grief.
- Bereavement staff makes visits to the patient and family/caregiver prior to the patient’s death in accordance with the plan of care.
- The hospice interdisciplinary team utilizes complementary therapies to assist in facilitation of a patient’s expressions of feelings.
- Children who are impacted by the patient’s death are identified and a plan is developed to respond to their needs.
- The patient and family/caregiver receive education regarding grief and loss.

Standard:

**PFC 16: Preparation for the family prior to the patient’s death and support for the family at the time of the patient’s death are provided.**
PFC 16.1 The hospice interdisciplinary team will, through written materials and verbal instructions, support families in understanding the signs and symptoms related to the final stages of illness and the dying process.

PFC 16.2 The hospice interdisciplinary team will ensure that families have opportunities to discuss their thoughts and feelings related to the final stages of illness, and to receive support in the ways that are meaningful to them.

PFC 16.3 Hospice interdisciplinary team members are available twenty-four (24) hours a day, seven (7) days a week to attend a patient death.

PFC 16.4 Hospice staff attending a death respect the cultural, religious, and spiritual traditions and beliefs of the patient and family/caregiver.

PFC 16.5 Each patient death is confirmed, documented, and communicated according to state law, regulation, and the hospice’s policy.

PFC 16.6 The patient’s body is handled with respect and dignity and in accordance with the requests of the patient and family/caregiver.

Practice Examples:
- Family members and caregivers are informed of standard notification procedures before death occurs.
- On-call services support the capability of staff attendance at all deaths in all settings.
- The appropriate hospice interdisciplinary team member attends and verifies a patient’s death per state regulations. The hospice has specific procedures related to documentation for patient death, including care of the body, disposal of medications per federal and state regulations, and other required notifications.
- Family members are afforded time with the patient’s body as desired and per cultural customs.
- On-call spiritual care staff is provided appropriate contact information for the family and other information to support the plan of care regarding cultural, religious, or spiritual traditions and beliefs of the patient and family/caregiver at the time of death.

Standard:

PFC 17: The hospice has a well-defined bereavement program that begins at start of care and provides services for a minimum of 13 months following the death of the patient.

PFC 17.1 The hospice has bereavement policies and procedures that delineate the scope of bereavement care provided and incorporate confidentiality procedures and mechanisms to assure that family preferences regarding bereavement contact are honored.
PFC 17.2 The hospice bereavement policies and procedures specify the services to be consistently provided within specific time frames during the course of bereavement care.

PFC 17.3 Guidelines for the hospice bereavement program clearly describe the nature of counseling services to be provided within specific time frames and the nature and constraints of such services.

PFC 17.4 The hospice has a systematic and ongoing method of evaluating the outcomes and effectiveness of the bereavement services provided.

PFC 17.5 The hospice defines eligibility criteria for bereavement services including consideration of the needs of bereaved members of the community.

Practice Examples:

- Bereavement services may include, but are not limited to:
  - Individual and family counseling;
  - Grief support groups, general and specialized, for all age groups;
  - Family support visits;
  - Telephone support;
  - Written materials about grief and coping that are appropriate for the age, language, average reading level, and special needs of the bereaved individuals served;
  - Scheduled mailings (e.g., personal, educational, and informational);
  - Memorial services and funerals;
  - Camps and retreats;
  - Spiritual and pastoral counseling;
  - Internal in-service programs;
  - External educational offerings; and
  - Referral to community resources.

- Bereavement counseling services are based on the understanding that grief is a normal part of life and can be navigated successfully with adequate support.

- Bereavement counseling for manifestations of non-complicated grief includes empathy and compassion, active listening, normalizing the grief experience, education, recognition of the bereaved person’s natural resilience, encouragement, problem-solving, and the reinforcement of adaptive coping strategies.

- Bereavement outcomes are identified and data are collected and analyzed on an ongoing basis to measure the effectiveness of services provided and develop strategies for improvement.

- A means of communicating with out-of-area family members is developed to provide bereavement information and to identify supportive resources in their area, if desired.

- Childhood loss and grief counseling and other programs are designed and provided consistent with bereaved children’s developmental phases and special needs.
Standard:

**PFC 18: A plan of care that includes bereavement needs, interventions, goals, and outcomes is developed and documented for families served by the bereavement program.**

**PFC 18.1** Goals and outcomes related to bereavement care are part of the ongoing care planning process and are determined by family members in collaboration with the hospice interdisciplinary team/bereavement staff.

**PFC 18.2** The plan of care for bereavement services should reflect family needs and delineate the specific services provided, including the means for service provision and frequency of contact.

**PFC 18.3** Bereavement needs, services, and interventions are documented in the patient clinical record during care of the patient, and in a separate record for the bereaved after the patient’s death.

**PFC 18.4** Routine bereavement services are available and offered to the family regardless of risk factors.

**PFC 18.5** Family members/caregivers whose needs are assessed to be beyond the scope of the hospice bereavement program are referred to appropriate community agencies or practitioners.

**Practice Examples:**

- The plan of care identifies the interventions to meet family needs and preferences, including frequency of contact.
- Bereavement goals and outcomes are regularly reviewed with the individuals who are receiving bereavement services.
- A plan is developed to address the needs of bereaved individuals who are identified as at risk for complicated grief reactions.
- A list of community resources or practitioners is maintained for referral of family members whose needs are assessed to be beyond the scope of the hospice bereavement program counseling services.
- A bereaved child’s record includes consent for care from the parent/guardian and ongoing communication of progress, needs, and therapies with the parent/guardian.

Standard:

**PFC 19: The hospice utilizes qualified staff and volunteers to provide bereavement services.**

**PFC 19.1** Bereavement services are managed and coordinated by qualified professional hospice staff with education and training appropriate to the position’s responsibilities.
PFC 19.2 Bereavement services are provided by appropriate hospice staff and volunteers who receive routine clinical supervision by qualified bereavement professionals.

**Practice Examples:**

- The hospice utilizes staff with degrees in clinical social work, mental health counseling, or other related fields (e.g., pastoral counseling) to provide bereavement services.
- Volunteers receive additional bereavement-specific training including but not limited to supportive listening, communication skills, general concepts of grief and loss including risk factors for complications in bereavement, professional boundaries, spiritual and/or religious boundaries, stress management, self-care, and collaboration and communication with the team/bereavement staff.
- The hospice ensures that clinical staff is comprehensively trained in loss, grief, and bereavement and are regularly offered continuing education opportunities in grief and loss, such as identifying high risk survivors and those at risk for complicated grief reactions.
- The hospice has a plan for providing regular and ongoing supervision of bereavement staff and volunteers.
- The hospice documents bereavement services provided.
- The hospice defines bereavement staff roles and responsibilities for providing bereavement support to clinical staff and volunteers.