

## Palliative Care

### About the Guideline

- RAND Evidence-based Practice Center conducted a complete review of the evidence with a consensus of expert practitioners and researchers.
- The purpose of the guideline is to present consistent criteria and standards for palliative care across all settings and to improve access for all patients.

### Key Clinical Considerations

#### **Structure and processes of care**

##### Interdisciplinary team (IDT)

- The interdisciplinary team includes physicians, nurses, social workers, advanced practice registered nurses, certified palliative care specialist, chaplains, and others (i.e., physical therapists, occupational therapists, music therapists, respiratory therapists, nursing assistants, and nutritionists) as needs arise.
- Physicians provide supervision to advanced practice registered nurses and physician assistants, determine the patient's prognosis, and conduct patient visits and medical treatments.
- Direct care is provided by the nurse and is guided by the assessments of the patient.
- When complex care is required, advanced practice registered nurses and physician assistants expand the care.
- Family dynamics and coping mechanisms are assessed by social workers.
- Spiritual issues are assessed and addressed by chaplains.
- Medication management is provided by clinical pharmacists.
- The IDT facilitates the setting of patient and family goals.
- Culturally sensitive care is developed by the IDT in conjunction with the patient and family.
- Staff care is available to the patient and family 24 hours/day and 7 days/week.
- The IDT works with community services, and provides referrals as needed, to help support the family.

##### Comprehensive palliative care assessment

- An assessment is completed after any referral.
- The initial assessment includes in-person discussions with the patient, family, and practitioners.
- Key aspects of the assessment include:
  - Evaluating the patient's and family's understanding of the illness
  - Establishing care goals and treatment preferences
  - Determining whether the patient has an advance directive, and who the legal authority is for decision-making
  - Performing a physical exam and completing a medical history
  - Reviewing the patient's medical record
  - Performing a medication reconciliation
  - Determining the patient's financial, safety, and housing situation
  - Assessing the patient's spiritual and emotional concerns, as well as grief and bereavement needs

- Providing the opportunity for the family, patient, and caregiver to communicate with each other

#### Palliative care plan

- The patient's needs, preferences, goals, values, and expectations for the plan of care should be discussed with the patient and family.
- The IDT works with the patient/family to discuss symptom management and treatment options in collaboration with other community providers and practitioners.
- The care plan is updated and reviewed on a regular basis and when a patient's status changes; this includes discussions on disease management and progression.
- Hospice referral is conducted as appropriate, as well as referral to additional practitioners to support the plan of care.
- If required, discussion may occur regarding alternative choices for care and treatment settings.

#### Continuity of palliative care

- The patient and family should be educated about the services and settings of palliative care, and written consent should be obtained.
- When palliative care services are discontinued, documentation of assessments and recommendations is done by the IDT and shared with the patient and family for any ongoing future care.
- When the patient dies, grief support is provided by the IDT, and the IDT ensures access to bereavement support.

#### Care settings

- The choice of care setting is determined by the preference of the patient and family.
- The goal is for the patient to have a sense of control and to provide the patient a safe environment.
- Visits from family, friends, and pets are facilitated by the care center in accordance with patient and family preferences and with policies of the facility.

#### IDT education

- All IDT members should have training and education in palliative care; this includes volunteers. Practitioners must meet state licensing requirements and understand their scope of practice.
- All IDT members should have specific training and education regarding opioids, which should include:
  - Appropriate and safe opioid use
  - Risk assessment for substance use disorder
  - Monitoring for signs of diversion and opioid abuse
  - Managing pain for patients at risk for substance abuse
  - Safe disposal of opioids

#### Coordination of care and care transitions

- Transitions should be anticipated and planned, while continuing to meet the patient's goals.
- Assessments should be performed after each transition of care.

#### Emotional support to the IDT

- Staff should be assessed for the emotional impacts of care including, grief, distress, and workload.

### **Physical aspects of care**

#### Global

- The IDT team focus is to improve quality of life and relieve suffering as per the patient's and family's definition of quality of life and suffering.
- The goals of care are to maintain functionality, physical well-being, and a quality of life that is acceptable to the patient.
- Recognize cultural influences when creating the plan of care.
- The IDT should provide symptom management for all serious illnesses.

#### Screening and assessment

- Use a medical interpreter as required to communicate in the preferred language of the patient and/or family.
- Ongoing assessments should be performed for pain, quality of life, and symptom distress, with reassessments to evaluate treatment effectiveness.
- Communication challenges may occur during assessments because of the patient's developmental capacity, injury, cognitive impairment, delirium, tracheostomy, intubation, or disease processes.
- The ability of the patient and/or caregiver to manage the patient needs or medication administration should be evaluated.

#### Treatment

- The ongoing management of treatment should be based on the patient's health status changes, physical symptoms, and risk factors related to treatment regimens.
- The patient and family should be encouraged to seek support, ask questions, and report status changes to the IDT.
- Reassess the patient to evaluate treatment responses.
- Collaborate with specialists as required to meet the needs of pediatric patients.
- Based on the patient's and family's preferences and needs, incorporate community services into the plan of care.
- Consider the risks, side effects, or potential for abuse when prescribing medications.
- Referrals should be made for rehabilitation therapies (i.e., speech, physical, and occupational) as required.

#### Ongoing care

- Document and collaborate with other practitioners involved with the patient's care.

### **Psychological and psychiatric aspects of care**

#### Global

- The IDT includes a social worker, whose goal is to support and assess any mental health issues and collaborate with other practitioners to maintain the psychological well-being of the patient and family.

- A safety plan should be in place for the patient, family, volunteers, and staff when caring for patients with psychiatric and psychological disorders.

#### Screening and assessment

- Assessments should include and evaluate the following:
  - Anxiety, depression, and emotional distress
  - Developmental or learning disabilities
  - Substance history, risk, or current use disorder
  - History or risk of attempted suicide
  - Previous or current posttraumatic stress disorder (PTSD)
  - Psychological distress and concerns related to cultural and spiritual considerations
  - Preexisting dual diagnosis of psychiatric/psychological conditions versus those resulting from the patient's illness (i.e., medication side effects and diagnosis depression)
  - Response to treatment, efficacy of treatment, and patient/family preferences
  - How the patient and family are coping with the illness
  - Assess the decision-making capacity of the health care surrogate

#### Treatment

- Provide psychiatric and psychological services through referral, consultation, or directly by the IDT members.
- Educate the patient and family regarding the disease or treatments, side effects, symptoms, and condition.
- Support the patient and family in decision-making.
- Emotional support should be provided to the patient and family in coping with postoperative complications or decisional regret.
- Support should be provided to the family related to caregiver burden, practical needs, and anticipatory grief.
- Address the emotional and mental health needs of perinatal families throughout the pregnancy, labor, and delivery, as well as postpartum.
- Ongoing care should be provided as required.

#### **Social aspects of care**

##### Global

- Recognize social factors that impact the patient's and family's quality of life.
- Care planning, care delivery, care management, and assessments should be based on the patient and family and be developmentally appropriate.
- Be aware of the financial impact of care, treatment, and medications on the family.
- IDT should assist with eligibility and benefit applications for Medicaid or other determined benefits.

#### Screening and assessment

- Screening should be culturally and developmentally appropriate for the patient.
- Assessment
  - Assess the family structure, including communication, quality of relationships, and decision-making preferences.

- Assess the strengths of the patient and family relating to spirituality, cultural, and social support.
- Assess the support system's ability to assist with chores, errands, and respite.
- Sexual and intimacy expression should be assessed in relation to the patient's injury or illness, including the risk of abuse, exploitation, or neglect.
- Activities of daily living (ADLs), cognition, and instrumental activities of daily living (IADLs) should be assessed in relation to any functional limitations the patient may have.
- Assess any Veterans' Affairs (VA) benefits for which the patient or family may be eligible.
- Assess the need for home modifications, adaptive equipment, or transportation.
- Assess the patient's and family's ability to meet financial needs, such as paying bills, prescriptions, or mortgage or rent.
- Evaluate the safety of living arrangements.
- Assess any changes in recreational activities, employment, economic security, and school enrollment for the patient or family.
- Assess food and nutritional needs.
- Address legal issues and advance care planning.
- Assess the willingness of the patient or family to accept referrals or resources, and the ability to understand insurance, social services, and health providers.

#### Treatment

- Encourage patient and family involvement in developing a plan of care with the IDT that reflects their values, strengths, preferences, and culture.
- Identify practitioners in the community for the amount and type of care they can provide.
- Identify outcomes for each goal.

#### Ongoing care

The IDT reviews and supports any providers and services involved in ongoing care.

#### **Spiritual, religious, and existential aspects of care**

##### Global

- Policies and processes should be clearly defined by the IDT and should be respectful of the age of the patient and family, as well as their culture, traditions, developmental needs, and spiritual preferences.
- Care should be provided in collaboration with a professional chaplain.
- Recognize any possible differences in spiritual needs between the family and the patient.
- Members of the IDT must not impose their own beliefs on the patient or family.

##### Screening and assessment

- Use standardized tools for gathering patient history and assessment screening.
- Evaluate for the absence or presence of spiritual distress or needs when screening.
- Assessment and evaluation should include the following:
  - Sources of support and strength
  - Concerns about God, meaning and suffering questions, anger at or abandonment by God
  - Loss of faith, spiritual practices, or community of faith struggles
  - Purpose, hope, and fears and values

- Preferences and cultural norms that influence spiritual practices and belief systems
- Quality of life concerns
- Fear of dying, death, and afterlife belief concerns
- Relationship concerns
- Grief and bereavement

#### Treatment

- Treatment should incorporate spiritual and cultural preferences related to the use of language and symbols.
- Children and adolescents' spiritual needs must be honored by the care team when they differ from their parents' beliefs, needs, and values.

#### Ongoing care

- As the needs of the patient and family change, the care plan should also progress.
- When new issues are identified, the IDT should reassess the spiritual needs of the patient and family.

#### **Cultural aspects of care**

##### Global

- Respect all values, cultural beliefs, language, and traditional practices of the patient and family.
- Determine the patient's definition of family and include all members.
- Understand the decision-making process of the patient's and family's culture relating to pain, illness, grief, death, and bereavement, as well as spiritual, social, and psychological factors.
- Culture includes gender expression and identity, ethnicity, social class, sexual orientation, abilities, physical appearance, spirituality, religion, and refugee status.
- The IDT should participate in educational training to increase their knowledge of culturally sensitive care.
- Assess the community to identify any underserved populations who may require palliative care.
- Ongoing evaluations should be performed when services, policies, and procedures need modification in terms of cultural sensitivity.

##### Communication and language

- Support the patient's and family's preferred type of communication and language.
- Adapt to their level of health literacy.
- Obtain a medical interpreter if English is not their first language of understanding or communication; utilize bilingual clinicians if a medical interpreter is not available.
- Ask for their preferred method of obtaining information and materials, using cultural images for the material.
- Written material should be provided in the patient's and family's preferred language.
- The patient's preferred pronouns should be used for all communication.
- Include a cultural representative in the plan of care, at the patient's or family's request.

##### Screening and assessment

- The IDT is nonjudgmental and is aware of potential biases.

- There should be awareness of any previous trauma and how the patient and family care may be impacted as a result.
- Assessment and evaluations should include the following:
  - Customs, cultural practices, and values related to the illness, process of dying, death, and post-death concerns
  - Patient's preferred gender identity, name, and pronouns
  - Determination of who will be interacting with the IDT for decision-making
  - What information should be shared with the patient and the family regarding diagnosis and prognosis related to cultural practice
  - Taboo practices (i.e., using certain words such as death and dying)
  - Resources available in the community for faith and cultural groups
  - Physical contact preference
  - Health literacy levels of understanding
  - Patient's understanding of their disability and illness
  - Beliefs about pain and suffering
  - Traditional healing practices or healers the patient and family may want included on the IDT
  - Approaches to seeking help from others
  - Acculturation levels within the patient's family that may impact decision-making
  - Defining how a minor's status impacts the role of the child or adolescent within the family
  - Parental definition of a “good parent”
  - Decision-making regarding foster children and siblings and their cultural preferences

### Treatment

Treatment should be implemented with respect to the cultural preferences of the patient and family, as defined in the previous sections.

### **Care of the patient nearing the end of life**

#### Training

- IDT members should have training and expertise in the care of patients and their families at the end of life. Training should include:
  - In-person or frequent telephone contact with the patient and family prior to death
  - Notifying friends or family as indicated by the patient and family
  - As death nears, managing and assessing physical symptoms such as dyspnea, pain, agitation, nausea, terminal secretions, and delirium
  - Discussing with the family what can be expected before death or once the patient dies
  - Discussing the approaching death with the patient and family
  - Discussing spiritual concerns about death and dying, and beliefs about the afterlife
  - Facilitating any cultural aspects and assessments related to care (i.e., beliefs and rituals)
  - Supporting the resolution of legal issues
  - Supporting any legacy-building activities (i.e., video diary, life review, or notes to friends and other family members)
  - Coordinating care transition
  - Assisting with hospice services and eligibility
  - Funeral planning and other post-death care

- Addressing the needs of any children or adolescents coping with the loss of a family member

#### Screening and assessment

- Know signs and symptoms nearing death.
- Support caregiver's and family's preparation and knowledge regarding common symptoms of the end of life.
- Review the decisions for treatment and confirm the patient's preferences and wishes and any associated documentation, including the advanced directive.
- Support the family by providing information regarding care.
- Discuss the benefits of hospice, if the patient has not accessed those services.
- Before death, discuss organ and tissue donation and autopsy concerns, following any relevant policies and laws.

#### Treatment prior to death

- Follow the developed plan during the dying process. Consider any spiritual and cultural preferences of the patient and family.
- Care at end-of-life includes psychological, social, clinical, and spiritual attention.
- Ensure supplies, medication, and equipment are accessible.
- Communicate with the family and or caregivers the expected symptoms at the end of life, what changes may occur, and what to expect after the patient dies. Confirm who to notify with any changes and/or if the patient dies.
- Provide grief support.

#### Treatment during the dying process and immediately after death

- Provide education related to signs and symptoms of impending death with appropriate language, both developmentally and culturally.
- Support the family after death, following any agency policies and practices, local and state laws, and regulations.
- Help the family with funeral arrangements (i.e., burial or cremation planning) according to their spiritual or cultural practices.
- Dispose of medications in accordance with disposal guidelines with the Drug Enforcement Administration (DEA) as well as the laws of local, state, and federal requirements.

#### Bereavement

- Support the family with individual or group counseling as desired.
- Provide resources for grief information.
- Provide an opportunity for family rituals for remembrance.
- Children who are grieving can be referred to programs, pediatric grief specialists, and camps based on their needs and age.
- Support for bereavement and grief should be based on the preference of the family regarding cultural, developmental, and spiritual needs.

#### **Ethical and legal aspects of care**

##### Global



- The core principles supporting palliative care provisions are substituted judgment (the surrogate and guardian have an ethical duty to understand the values and beliefs of the patient prior to making any decisions on behalf of the patient), autonomy, justice, beneficence, and nonmaleficence.
- In all care settings, palliative care is modeled on respect for codes of ethics, scopes of practice, conflicts of interest, and standards of care for all related disciplines.
- Staff education should be provided by an ethics guide policy that includes the following areas:
  - Nonbeneficial care is defined as a treatment that does not have any potential, based on current medical experience, to enhance to the patient's goals of care or well-being.
  - A right for the patient to refuse any treatments
  - Stopping medically provided nutrition and hydration
  - Discontinuing or not starting technology (i.e., dialysis and ventilators)
  - High-dose medication
  - Sedation for actively dying patients
  - Physician-assisted death requests
  - Maintenance of professional boundaries and clear expectations of IDT roles with the patient, family, and caregivers
  - Allocation of resources related to costs of care and social justice principles
  - Surrogate decision-maker guidance based on the patient's preferences and best interest

#### Legal considerations

- All IDT members should be knowledgeable in all state and federal statutes, laws, and regulations as well as organizational policies related to the following:
  - Disclosing health information and medical records
  - Advance directives and advance care planning
  - Neglect and abuse
  - Guardianship
  - Controlled substance prescribing
  - Pediatric patient hospice care provisions
  - Medical decision-making
  - Pronouncement of death and processes for issuing death certificates
  - Anatomical and organ donation and requests for an autopsy
  - Developing issues (i.e., opioid abuse, physician-assisted dying, and medical marijuana)
  - Gifts to patients, caregivers, and families, as they relate to conflicts of interest
  - Proactive encouragement to families and parents to update or create financial and legal documents (i.e., guardianships, wills, and custody)
- Screening and assessment should include the following:
  - Advance care planning
  - Living wills
  - Do not resuscitate (DNR) orders
- As patient preferences, desires, and decisions change, the IDT should update their plan of care.
- The IDT is required to follow state law to identify a default decision-maker in the following circumstances: in the case of patient incapacity or impairment; if the patient is developmentally unable; if there is a change in the patient's cognition; or when a patient has not expressed their beliefs, values, or preferences.

- Assess, document, and incorporate into decision-making the preferences and views of pediatric patients.

#### Treatment and ongoing decision-making

- Treatments should align with the standards of care, the team, and the patient's goals.
- It is an ethical concern when patient preferences are not honored.
- Treatments are provided to reduce the suffering of the patient with a distinction made between foreseen consequences and intended consequences.
- The cost of care and the financial burdens of treatment options should be provided to the patient and family.
- The principle of nonmaleficence must be ensured when treatments are discontinued or forgone.
- Children should be given the opportunity to make decisions about their care based on their developmental capacity, age, and wishes.
- If there is a conflict with what the patient wishes or what the surrogate expresses and what the practitioners believe is required, patients should never feel their care is not safe, and they should know that quality care will still be provided.

#### **Reference:**

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care*, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care.

#### **Link to Practice Guideline:**

[https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf)