Principles:

- Upholding high standards of ethical conduct and advocating for the rights of patients and their family caregivers.
- The hospice respects and honors the rights of each patient and family it serves.
- The hospice assumes responsibility for ethical decision-making and behavior related to the provision of hospice care.

For more detail on issues discussed in this chapter, please refer to NHPCO's Ethical Principles: Guidelines for Hospice and Palliative Care Clinical and Organizational Conduct. Advance care planning information and state-specific advance directives are available through NHPCO's Caring Connections at www.caringinfo.org.
**Standard:**

**EBR 1** Hospice patients and families have the right to be involved in all decisions regarding their care, treatment and services.

**EBR 1.1** Patients and families are given an explanation at the time of admission of the hospice program’s focus on palliative care.

**EBR 1.2** Informed consent for hospice care is obtained from the patient or designated representative and documented in the clinical record.

**EBR 1.3** The hospice verifies the patient’s advance directive status and documents pertinent information in the clinical record.

**EBR 1.4** The hospice educates the patient on the importance of an advance directive and assists the patient in completing an advance directive if requested.

**EBR 1.5** The patient’s wishes are respected and taken into consideration when planning for the patient’s care and are documented in the clinical record.

**EBR 1.6** Decisions regarding care or services to be provided are communicated to the patient and family and documented in the clinical record.

**EBR 1.7** The hospice provides each patient and family with a notice of rights and responsibilities prior to the furnishing of care to patients and families.

**EBR 1.8** Patients and families are informed when services are first provided of any potential of cost.

**Practice Examples:**

- On admission and prior to rendering care, the hospice educates each patient about his or her right to formulate an advance directive. The patient has the right to not develop an advance directive. The decision is documented in the clinical record.

- Family satisfaction surveys include a question related to the hospice’s consideration of the patient’s wishes (e.g., *did the patient receive any unwanted medical intervention?*).

- The patient’s status and desires related to end-of-life decisions are evaluated and documented in the psychosocial assessment.

- When the hospice is not able to obtain a copy of the patient’s executed advance directive, a staff member documents the patient’s preferences regarding treatment choices, designation of a surrogate, etc. in the clinical record.

- When the needs/goals of the patient differ from those of their family, the hospice ensures that the preferences of the patient are met and work with the family to gain acceptance of the patient’s goals.

- The hospice admits a patient that does not understand English. The hospice must provide a translator and may have to offer written material in their native language. The use of the family as a translator is discouraged, except when the spoken language is uncommon and a translator is not available.
Standard:

**EBR 2** Hospice patients and families have the right to confidentiality.

**EBR 2.1** The hospice has written policies and procedures regarding confidentiality and the protection of information from inappropriate and/or unlawful disclosure.

**EBR 2.2** When data is collected and aggregated, individual patient confidentiality is protected.

**EBR 2.3** Staff are educated about patient confidentiality and the hospice’s policies and procedures related to confidentiality, privacy and security.

**EBR 2.4** All staff, including volunteers, agree in writing to maintain patient confidentiality during orientation or prior to having any contact with patient, family or caregiver information.

**EBR 2.5** The hospice is in compliance with the Health Insurance Portability and Accountability Act (HIPAA).

**Practice Examples:**

- Any patient information carried in staff vehicles is handled in a manner so that patient names, diagnoses or clinical reports are not observable.

- Hospice aides know how to respond appropriately when asked by other concerned individuals about patients they are visiting.

- Staff assures that patient, family and caregiver information is not left exposed in work areas and uses tools such as computer privacy screens.

- The hospice has defined procedures for the disposal of documents that contain patient, family and caregiver information, such as a paper shredder.
Standard:

**EBR 3** Patients and families have the right to have their complaints heard and addressed.

- **EBR 3.1** The hospice has a complaint resolution process in place and implements this process whenever a concern/complaint is received.
- **EBR 3.2** The hospice informs patients and families of the complaint resolution process at the time of admission.
- **EBR 3.3** Complaints are tracked and regularly reviewed to identify any patterns or trends.
- **EBR 3.4** Staff are educated about the complaint resolution process and accepts responsibility for helping identify and address complaints.

**Practice Examples:**

- A complaint log is maintained and includes the complaint, source of the complaint and documentation of efforts toward resolution.
- A written summary of the types of complaints received is developed periodically *(e.g., quarterly)* and problem areas are identified and addressed.
- The interdisciplinary team reviews any patient, family and caregiver complaints about care provided and take remedial action as appropriate.
- There is a designated person in the hospice that is responsible for complaint follow up, resolution and documentation.
- The complaint process is provided in writing to the patient and family, listing specific contact names and numbers.
- The staff is educated in complaint resolution techniques that are constructive and do not place blame on others.
ETHICAL BEHAVIOR AND CONSUMER RIGHTS (EBR)

Standard:

EBR 4  The hospice acknowledges and respects each patient’s and family’s rights and responsibilities.

These rights include:
◆ Effective management of pain and symptoms;
◆ Involvement in care plan development;
◆ Refusal of care or treatment;
◆ Choice of attending physician;
◆ Confidentiality of information;
◆ Freedom from abuse;
◆ Information about the hospice benefit; and
◆ Information about services and limitations of hospice service.

EBR 4.1  The hospice provides a statement to each patient, family and caregiver on admission of their rights and responsibilities and makes the document available to the community.

EBR 4.2  The hospice has written policies and procedures that address:
1. The purpose and scope of hospice services;
2. Informed consent by the patient/family to hospice services;
3. Surrogate consent according to state laws; and
4. Staff education related to patient and family rights and responsibilities.

EBR 4.3  There is signed documentation in the clinical record acknowledging that the patient, family and caregiver received an explanation of their rights and responsibilities.

Practice Examples:

◆ The clinical record review process verifies that each patient, family and caregiver received an explanation of their rights and responsibilities.

◆ A statement of the hospice patients’ and families’ rights is included in each admission packet or booklet.

◆ Family members are informed at the time of admission of the consequences for certain decisions that impact the care of the patient (e.g., calling 911, obtaining unauthorized services, etc.).
**Standard:**

**EBR 5** Each member of the interdisciplinary team recognizes and demonstrates a fiduciary relationship, maintains professional boundaries and understands that it is his/her personal responsibility to maintain appropriate relationships with the patient, family and caregiver.

**EBR 5.1** The hospice provides orientation and training for staff and volunteers regarding the patient’s rights and responsibilities.

**EBR 5.2** The patient and family have the right to be respected and to express a grievance and not to be subject to discrimination or reprisal.

**Practice Examples:**

- Hospice staff, board members and volunteer personnel records include a signed conflict of interest statement on an annual basis that addresses both paid and unpaid staff.

- Hospice policy states staff should not communicate with the media without the administration’s knowledge or permission. Information used for the purpose of promoting the hospice programs is done only with the written consent of the patient/family/caregiver.

- The hospice has a policy that addresses accepting of money or gifts from patients or family members.

- Hospice staff do not give patients or family members their home telephone numbers but rather refer them to the hospice’s telephone number to call after normal business hours for service.

- The hospice provides orientation and training for staff and volunteers regarding the establishment and maintenance of professional boundaries with this vulnerable population.