

STANDARDS OF PRACTICE FOR HOSPICE PROGRAMS

PROFESSIONAL DEVELOPMENT AND RESOURCE SERIES

4 / Ethical Behavior and Consumer Rights (EBR)

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PRINCIPLE

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 [*Guide to Organizational Ethics in Hospice Care*](#) (2016).

Advance care planning information and state-specific advance directives are available through NHPCO's Caring Connections at www.caringinfo.org

Standard:

EBR 1: The hospice maintains the right of the patient, as well as the family/caregiver, to be involved in all decisions regarding care, treatment, and services.

EBR 1.1 Patients and families/caregivers are provided education and opportunities to review the hospice approach to care, treatment, and focus on palliative care services at the time of admission and throughout the course of care.

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

EBR 1.3 The hospice obtains information related to the patient's advance care planning status, conditions, and specifications. The hospice documents the information in the clinical record.

EBR 1.4 The hospice educates the patient and family/caregiver on the importance and benefit of advance care planning and identifies additional resources for 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. The hospice documents the patient's wishes in the clinical record.

EBR 1.6 The organization respects the patient's rights to choose and discontinue hospice services.

EBR 1.7 Decisions regarding care or services to be provided are based on the patient's and family/caregiver's goals for care, are communicated to the patient and family/caregiver, and are documented in the clinical record.

EBR 1.8 The hospice provides verbal explanation and written information about the organization's policies on advance directives, including a description of relevant state law.

EBR 1.9 Prior to provision of service or any change in service, the hospice informs patients and families of policies regarding discontinuing services and any potential costs to them. The hospice documents the patient's or the financially responsible party's understanding of that information.

Practice Examples:

- On admission, the hospice educates the patient and family/caregiver about hospice care and specific hospice services. In addition, the hospice explains insurance coverage and patient rights under that coverage.
- Families/caregivers are made aware of all services available to them, including psychosocial, spiritual, volunteer, and bereavement services.
- The hospice has a written policy that includes a clear and precise statement of limitation if a staff member or the hospice program cannot implement an advance directive, treatment, or procedure on the basis of conscience.
- On admission and prior to provision of care, the hospice educates each patient about his or her right to formulate an advance directive. The patient's decision is documented in the clinical record.
- The patient's status and desires related to end-of-life care decisions are documented in the psychosocial assessment.
- The hospice does not require specific provisions in advance directives, such as a Do Not Resuscitate (DNR) order, as a condition for admission.
- The hospice has a process in place to ensure that the patient's designated representative has the authority to make decisions on behalf of the patient in accordance with state laws and regulations.
- When the needs/goals of the patient differ from those of the family, the hospice ensures that the preferences of the patient are met and works with the family to gain acceptance of the patient's goals.
- The hospice provides translational services for patients who do not understand English. Written materials are developed in the patient's preferred language as needed. The hospice uses a family member/caregiver as translator only when (1) the patient's native language is uncommon and a translator is not available after effort to locate one, and (2) the patient consents or specifically requests a family member/caregiver as the translator.
- The hospice consults United States Census information or the Office of Civil Rights (OCR) list of the top 15 languages spoken by individuals with Limited English Proficiency (LEG) in each state, the District of Columbia, and each U.S. Territory - [PDF](#) to determine prevalence of various languages in the service area and makes written materials available in languages commonly found in the service area covered by the hospice.

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, which conform to federal regulations.

EBR 2.2 Individual patient confidentiality is protected by obtaining signed approval from the patient or designated representative for recordings, films, or other images and in data collection, aggregation, and submission to an outside entity.

EBR 2.3 All staff members, including volunteers, are educated about patient confidentiality and the hospice's policies and procedures related to confidentiality, privacy, and security.

EBR 2.4 During orientation and prior to any exposure to patient or family caregiver information, all staff members, including volunteers, agree to maintain patient confidentiality in writing.

EBR 2.5 The hospice maintains compliance with all components of the Health Insurance Portability and Accountability Act (HIPAA) and discloses health information only as authorized and in accordance with laws and regulations.

Practice Examples:

- Any patient information carried in staff vehicles is handled in a manner so that patient names, diagnoses, or clinical reports are not discernable.
- Hospice staff members know how to respond appropriately when asked by concerned individuals about patients.
- Staff ensures that patients' protected health information is not left exposed in work areas and uses security tools such as computer privacy screens.
- The hospice has defined procedures for the disposal of documents that contain protected health information, such as use of a paper shredder or shredding service.
- The hospice's electronic records and communications accessed through portable devices (laptops, cell phones, etc.) meet HIPAA/HITECH requirements and guidelines regarding passwords, locking, and secure networks.

Standard:

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

EBR 3.1 The hospice has a process in place that is initiated whenever a complaint is received to work toward resolution of the complaint. The hospice documents this process and resolution, including the follow-up performed with patient/family/caregiver.

EBR 3.2 At the time of admission, the hospice informs patients and families/caregivers of both the hospice's internal complaint resolution process and external processes, and provides a list of external bodies where complaints can be filed along with information on how to contact them.

EBR 3.3 Complaints are tracked and regularly reviewed to identify any patterns or trends.

EBR 3.4 Staff members are educated about the complaint resolution process and accept responsibility for helping to identify and address complaints.

EBR 3.2 The patient's and family/caregiver's views are respected and their expression of a grievance does not result in discrimination or reprisal.

Practice Examples:

- A complaint log is maintained and includes the complaint, source of the complaint, documentation of efforts toward resolution, and final resolution.
- A written summary of the types of complaints received is developed periodically (e.g., quarterly) and problem areas are identified and addressed.
- The hospice interdisciplinary team reviews any patient or family complaints about care provided and takes remedial action as appropriate.
- The hospice designates a staff member who is responsible for complaint follow-up, resolution, and documentation.
- Information on how to voice a complaint is provided in writing to the patient and family/caregiver, listing specific contact names and numbers of hospice leadership staff and the contact information for the state survey agency.
- The staff is educated in complaint resolution techniques that are constructive and do not place blame on others.
- Information gathered through the complaint process is regularly monitored as part of the hospice's QAPI program. Trends are identified as opportunities for improvement in care and outcomes.

Standard:

EBR 4: The hospice acknowledges and respects each patient's and family/caregiver's rights and responsibilities.

These include the right to:

1. Being treated with respect;
2. Quality end-of-life care;
3. Effective management of pain and symptoms;
4. Involvement in care plan development;

5. Refusal of care or treatment;
6. Choice of attending physician;
7. Confidentiality of information;
8. Freedom from abuse, mistreatment, and neglect;
9. Information about hospice insurance coverage;
10. Information on advance directives
11. Information about services and limitations of hospice service;
12. Freedom from discrimination or reprisal for exercising his or her rights; and
13. A medical record.

EBR 4.1 Upon admission, the hospice informs each patient and family/caregiver of the hospice patient's rights both verbally and through a written statement.

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 for the provision of hospice services;
3. Designated representative consent according to state laws; and
4. Staff education related to patient and family/caregiver rights and responsibilities.

EBR 4.3 Signed documentation acknowledging that the patient and family/caregiver received an explanation of the patient's rights is included in the patient's medical record.

Practice Examples:

- The hospice has a clinical record review process to verify that each patient and family/caregiver received an explanation of the patient's rights and responsibilities.
- A statement of hospice patient rights is included in each admission packet or booklet.
- The hospice explains patient rights and responsibilities in a manner the patient and family/caregiver can understand during the admission visit.
- Family members/caregivers are informed at the time of admission of the consequences for certain decisions that may impact the care of the patient (e.g., calling 911, obtaining unauthorized services).

Standard:

EBR 5: Each member of the hospice 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 caregivers.

EBR 5.1 The hospice provides orientation and training for staff, including volunteers, regarding the patient's rights and responsibilities.

EBR 5.2 The hospice provides orientation and training for staff, including volunteers, regarding the importance, principles, and maintenance of professional boundaries.

EBR 5.3 The hospice provides orientation and training for staff, including volunteers, regarding the fiduciary responsibility of the hospice to protect the interests of patients and families, including prohibited conflicts of interest.

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 may not communicate with the media without the administration's knowledge or permission.
- The hospice has a policy that addresses accepting of money or gifts from patients or family members.
- Hospice staff members, including volunteers, do not give patients or family members/caregivers their personal contact information (home phone numbers, cell phone numbers, email addresses).

Standard:

EBR 6: The hospice has a mechanism in place to assist the hospice interdisciplinary team when ethical conflicts or dilemmas arise during the provision of care to patients and families/caregivers.

EBR 6.1 The hospice establishes procedures to identify, review, and discuss ethical dilemmas that cannot be resolved by professional practice guidelines or hospice policies and procedures.

EBR 6.2 Hospice staff members are educated about ethics in hospice care and the hospice program's procedures for addressing ethical issues.

Practice Examples:

- The hospice staff has access to an ethics committee that meets to review ethical considerations related to patient care or end-of-life care issues (e.g., requests for physician assisted death, pediatric care, withdrawal of life-sustaining care or life support, caregiver safety).
- The hospice has a policy that addresses the withdrawal of life-sustaining interventions (e.g., enteral or parenteral nutrition, implanted cardiac defibrillator, ventilator).
- The hospice includes an ethics component in orientation for new staff and volunteers.
- The hospice has a Code of Ethics to guide ethical decision making.
- New hospice clinical staff members complete a competency-based educational module on ethics as part of orientation.

- Hospice team members are able to identify common ethical issues or dilemmas in hospice care and how they can be addressed.

Standard:

EBR 7: The hospice acknowledges and respects the rights and responsibilities of its volunteers and supports and empowers them in the fulfillment of their role.

EBR 7.1 The hospice has written guidelines that encourage surviving family members/caregivers to wait a minimum of one year following the patient's death before serving as a volunteer.

EBR 7.2 The hospice has a process to screen and evaluate individuals who wish to serve in a volunteer capacity to ensure compliance with established qualifications and regulations for hospice volunteers.

EBR 7.3 The hospice has written guidelines for employees related to working with volunteers.

EBR 7.4 The hospice fully orients volunteers to the role and expectations of the hospice volunteer, including the importance of maintaining boundaries with patients and caregivers.

EBR 7.5 The hospice provides clear role delineation guidelines for its volunteers and ensures that each individual volunteer assignment is within the scope of the accepted role and duties of hospice volunteers.

EBR 7.6 The hospice provides ongoing supervision and access to support for volunteers.

Practice Examples:

- Volunteer recruitment brochures clearly identify qualifications pertaining to volunteering after a death in the family.
- New volunteer orientation includes training related to maintaining boundaries with patients and families/caregivers.
- The volunteer coordinator maintains close contact with, and provides individualized support for, all volunteers who provide direct patient care. The volunteer coordinator pays particular attention to identifying potential conflicts of interest, ethics violations, and burnout.

Standard

EBR 8: The hospice ensures that all alleged violations of patient rights are reported immediately by the hospice staff, including contracted and arranged service providers, to the hospice administrator or a staff designee for appropriate action.

EBR 8.1 The hospice has written policies and procedures that guide the reporting of alleged violations and caregiver misconduct, and include required time frames for reporting.

EBR 8.2 The hospice administrator or staff designee investigates alleged violations and, if verified, the hospice reports the violation to state and federal authorities in the timeframe required by law.

EBR 8.3 The hospice administrator or staff designee assesses the current safety and comfort of the patient at the time of the reported allegation.

Practice Example:

The hospice observes a facility staff member mistreat a patient in a facility. They report what they saw to the hospice administrator and facility administrator for investigation according to their policy.

Standard

EBR 9: The hospice keeps the interests of the patient and family/caregiver, and provision of high quality care, a priority in all business practices.

EBR 9.1 The hospice has processes in place to ensure program integrity, accountability, and transparency in its business practices.

EBR 9.2 Business and marketing practices are carried out within the parameters of all relevant legal and regulatory frameworks.

EBR 9.3 Admission and discharge practices maximize access to care for all patients who meet eligibility requirements for receiving hospice care.

EBR 9.4 The hospice truthfully and accurately represents its capacity and services in all marketing, outreach, and education activities and media.

EBR 9.5 Involvement of patients and families in marketing and outreach are conducted so that their confidentiality, privacy, and physical and emotional wellbeing are maintained and respected.

Practice Examples:

- The hospice discloses any ownership interests or business relationships between the referral source and the hospice to every patient and family/caregiver.
- Before using patient/family/caregiver stories, testimonials and images in marketing materials, a valid signed patient/family agreement is obtained using a clearly stated consent form.
- When doing informational presentations, the hospice liaison nurse describes the full range of services available and the limitations of those services (e.g., the hospice does not provide hospice aides for round-the-clock custodial care).
- The hospice provides the option of opting out of receiving information related to the hospice's marketing and outreach activities to all patients and families/caregivers.