



NHPCO'S Standards of Practice

Ethical Behavior and
Consumer Rights (EBR)

2022 Edition

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Principles

A hospice upholds high standards of ethical conduct and advocates 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.

Advance care planning information and state-specific advance directives are available through NHPCO's CaringInfo, which provides free resources to educate and empower patients and caregivers to make decisions about serious illness and end-of-life care and services. For more information about CaringInfo, visit www.caringinfo.org.

Standard:

EBR 1: The hospice maintains the patient's right to be involved in all decisions regarding the patient's care, treatment, and services.

EBR 1.1 Patients are provided education and opportunities to review the hospice's approach to care, treatment, and focus on palliative care services at the time of admission and throughout the course of care. Families/caregivers are involved per patient wishes or surrogate state-based decision-making laws are followed, as applicable.

EBR 1.2 Informed consent for hospice care is obtained from the patient or legally authorized 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; educates the patient and family/caregiver on the importance and benefits of advance care planning; and identifies additional resources for completing an advance directive, if requested. The hospice documents the information in the clinical record for patients of all ages.

EBR 1.4 Decisions regarding care or services to be provided are based on the patient's (or legally authorized representative) preferences and goals for care, are communicated to the patient and family/caregiver, and are documented in the clinical record.

EBR 1.5 The organization respects the patient's right to choose and discontinue hospice services.

EBR 1.6 The hospice provides verbal explanation and written information about the organization's policies on advance directives, including a description of relevant state law(s).

EBR 1.7 Prior to the provision of services or any change in services, 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.

EBR 1.8 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.

EBR 1.9 The hospice provides interpretation and translational services for patients with limited English proficiency (LEP). Written materials are developed in the patient's preferred language as needed or desired.

EBR 1.10 The hospice has a process in place to ensure that the patient's designated representative is identified and confirmed and has the authority to make decisions on behalf of the patient in accordance with state laws and regulations.

EBR 1.11 The hospice has a written policy that includes a clear and precise statement of limitations if a staff member or the hospice program cannot implement the legally authorized surrogate's treatment request, whether in the form of a real-time written or verbal request, or an advance directive based on conscience.

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 core hospice services available to them, including psychosocial, spiritual, volunteer, and bereavement services.
- On admission and prior to provision of care, the hospice educates each patient about their right to formulate an advance directive. The patient's decision is documented in the clinical record.
- The patient's (or their legally-authorized representative's) desires related to end-of-life care decisions are documented in the psychosocial assessment, which is a part of the overall comprehensive assessment.
- The hospice does not require specific provisions in advance directives (e.g., a Do Not Resuscitate (DNR) order) as a condition of admission.
- The hospice consults United States Census information or the Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) list of the top 15 languages spoken by individuals with LEP in each state, the District of Columbia, and each U.S. Territory (see HHS website for more information) to determine prevalence of various languages in the service area and makes written materials available in languages commonly found in the hospice's service area.

Standard:

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

EBR 2.1 The hospice has written policies and procedures regarding privacy and the protection of information from inappropriate and/or unlawful disclosure, which conform to federal regulations and recognize that patients may be entitled to confidentiality from disclosure to family or caregivers.

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 patients' rights to privacy and the hospice's obligation to confidentiality through policies and procedures.

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

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 federal and state laws and regulations.

Practice Examples:

- Any patient information carried in staff vehicles is handled in a manner such that patient names, diagnoses, or clinical reports are not discernable.
- The hospice staff asks for the patient's permission before touching the patient.
- The hospice staff know how to respond appropriately when asked by concerned individuals about patients.
- The hospice staff ensure that patients' protected health information is not left exposed in open 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 other shredding service.
- The hospice's electronic records and communications accessed through portable devices (e.g., laptops, cell phones, etc.) meet HIPAA and Health Information Technology for Economic and Clinical Health (HITECH) requirements and guidelines regarding passwords, locking, and secure networks.

Standard:

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

EBR 3.1 The hospice has a formal 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 the patient/family/caregiver.

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

EBR 3.3 Complaints are tracked via a complaint log 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 3.5 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:

- The hospice interdisciplinary team reviews any patient or family complaints about care provided and takes timely, 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 Quality Assurance and Performance Improvement (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 patient's and family/caregiver's right to:

- Be treated with respect;
- Receive quality end-of-life care;
- Receive effective pain and symptom management;
- Be involved in care plan development;
- Refuse care or treatment;
- Choose their attending physician (e.g., a patient has the right to request their personal/community physician remain their attending physician if the personal/community physician is willing);
- Confidentiality of information;
- Be free from abuse, mistreatment, and neglect;
- Receive information about hospice insurance coverage and patient cost-sharing;
- Receive information on advance directives
- Receive information about hospice services and limitations thereof;
- Be free from discrimination or reprisal for exercising their rights; and
- Access and request a copy their clinical record.

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

EBR 4.2 The hospice has written policies and procedures that address:

- The purpose and scope of hospice services;
- Informed consent by the patient/family for the provision of hospice services;
- Authorized designated or legal/authorized representative consent according to state laws; and
- Staff education related to patient and family/caregiver rights and responsibilities.

EBR 4.3 Signed documentation acknowledging 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 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 the patient's rights and responsibilities in a manner the patient and family/caregiver understand during the admission visit.
- Family/caregivers are informed at the time of admission of the consequences for certain decisions that may impact patient care (e.g., calling 911, obtaining unauthorized services).
- Hospice staff address the patient by their preferred name.
- Hospice staff report all suspected or actual incidences of mistreatment, neglect, abuse(s), or injuries of unknown source and misappropriation of patient property.
- Hospice leadership investigate all suspected or actual incidences of mistreatment, neglect, abuse(s), or injuries of unknown source and misappropriation of patient property through interviews, observations, record reviews, and other appropriate means.
- Hospice staff review written advance directives with the patient or authorized legal representative to determine, understand, and validate the patient's current wishes for care.
- Hospice staff work with the patient's designated family members to review the patient's advance care directives and wishes for care.

Standard:

EBR 5: Each hospice interdisciplinary team member recognizes and demonstrates a fiduciary relationship, maintains professional boundaries, and understands that it is their 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 acceptance of money or gifts from patients or family members.
- The hospice develops a policy that restricts hospice staff, including volunteers, from giving patients or family members/caregivers their personal contact information (e.g., home phone numbers, cell phone numbers, email addresses).

Standard:

EBR 6: The hospice has a mechanism in place to assist the hospice interdisciplinary team to resolve conflicts or uncertainties about values that arise during the provision of care to patients and families/caregivers.

EBR 6.1 The hospice establishes procedures (e.g., an ethics consultation service) 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 are educated about ethics in hospice care and the hospice program's procedures for addressing ethical issues.

EBR 6.3 All referrals to ethics consultation service are tracked via an ethics consult log and regularly reviewed to identify any patterns or trends.

EBR 6.4 Hospice has a comprehensive ethics policy that addresses key topics such as composition and responsibilities of an ethics committee (e.g., membership, training and records, and ethics consultation service).

Practice Examples:

- The hospice has access to an ethics committee or ethical expertise. This may include a hospice's consultation with a trained clinical ethicist to review and discuss 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, and caregiver safety).
- The hospice policy on ethics consultation notes that a physician order is not needed for an ethics consult.
- The hospice has a policy that addresses the withdrawal of life-sustaining interventions (e.g., enteral and 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 complete a competency-based educational module on ethics as part of orientation.

Standard:

EBR 7: The hospice acknowledges and respects the rights and responsibilities of volunteers, supporting and empowering them in 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 hospice 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 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 in accordance with Federal and/or state law.

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:

- If hospice staff observe evidence of potential or actual mistreatment of a patient, they must immediately report what they saw to the hospice administrator (and facility administrator if patient resides in a nursing facility), as indicated, for investigation according to the hospice 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 ethical, legal, and regulatory frameworks (see NHPCO Resource: Hospice and Palliative Care: Ethical Marketing Practices).

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 to every patient and family/caregiver any ownership interests or business relationships between the referral source and the hospice.
- A valid signed patient/family agreement is obtained by the hospice, using a clearly stated consent form, prior to using patient/family/caregiver stories, testimonials, and images in marketing materials.
- When doing informational presentations, hospice staff describe 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, provision of like medications from organization's formulary, and not providing CPR if patient is in a full code and hospice staff is not CPR certified).
- The hospice provides the option to all patients and families/caregivers of opting out of receiving information related to the hospice's marketing and outreach activities.



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