ETHICAL PRINCIPLES: GUIDELINES FOR HOSPICE AND PALLIATIVE CARE
CLINICAL AND ORGANIZATIONAL CONDUCT*

*Formerly published as “Vital Bonds” by NHPCO, 2001
HOSPICE AND PALLIATIVE CARE PREAMBLE

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care services provide a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. These services are delivered with sensitivity to the fact that, as hospice and palliative professionals, we have entered into people's lives and affairs during a period of heightened need and potential vulnerability.

Through its work in supporting providers and professionals and offering education to the public, the National Hospice and Palliative Care Organization serves as an advocate for patients facing the end of life and their families. Through its standards, policies and procedures, NHPCO seeks to promote an ethical corporate culture among its members, involving both internal and external relationships. NHPCO encourages all its members to provide services which are grounded in fundamental ethical principles of healthcare. These principles include Autonomy, Beneficence, Nonmaleficence, and Justice. In addition to these four, Conscientious Objection is a highly held principle, encouraging people to speak up when a situation or circumstance is contrary to their beliefs.

The National Hospice and Palliative Care Organization offers this Hospice and Palliative Care Code of Ethics as a guideline to hospice and palliative care programs and professionals to assist them in assuring that hospice and palliative care throughout the country is provided in accordance with the highest standards of ethical behavior.

Recognizing that situations do and will arise when ethical principles conflict, the National Hospice and Palliative Care Organization recommends that every hospice and palliative care program have a process and format in place to deal with situations arising from these conflicts.
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The National Hospice and Palliative Care Organization (NHPCO) advances the philosophy and practice of hospice and palliative care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. NHPCO serves as a voice and resource for its members and the field of hospice and palliative care.

NHPCO envisions a world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer. Our mission is to lead and mobilize social change for improved care at the end of life.

Those seeking to improve the quality of life for people nearing the end of life must assume the responsibility of great trust. This responsibility goes beyond legal or business obligations. It is a crucial relationship that must be well tended and nourished. In fact, the patient and family are, and must be, the center around which every conversation, decision, and action of the organization revolves.

NHPCO believes it is crucial to establish ethical guidelines that will help assess our accountability to the individuals and the communities we serve. Though common sense is foundational, it is not sufficient in providing guidance to hospice and palliative care professionals as they navigate the complex and often confusing waters of the hospice and palliative care field.

An organization with clearly articulated ethical principles, and a thorough commitment to those principles, is better positioned to respond more effectively in times of crisis and change than one without such guidelines.

These guidelines build upon the previous policies and guidelines that NHPCO has developed (see Resources section in the Appendix). While these documents provide direction, the current business environment in healthcare and the world in general, has created the need for additional attention to ethical and transparent business, clinical, and organizational practices.
The rapidly changing healthcare environment and the ever-increasing pressures on healthcare providers often lead to a feeling of uncertainty regarding “the right thing to do.” Fundamental political shifts, emergence of managed care, increasing competition, consolidation, downsizing in the general healthcare arena, technological advances, potential workforce shortages, and an atmosphere of intense government, media, community, and citizen scrutiny have led to a situation in which new and difficult legal and ethical issues are regularly presenting hospice and palliative care leaders with difficult business and organizational decisions.

While the issues above play an important role in healthcare, hospice and palliative care organizations, many of the overwhelming ethical issues do not have a business or legal orientation, but are intimate, profoundly personal life and death situations involving relationships between end-of-life care professionals and those for whom they are providing care. These relationships and the manner in which they are handled are critical to gaining and keeping the trust of the patient, family and the public, which is the essential basis for the work of hospice and palliative care.

An increased awareness of individual and organizational ethics can build a culture that celebrates trust — a culture that is also compliant with laws and regulations. It also encourages a commitment to a sustained ethical environment that can be a direct force in heightening the excellence, efficiency, productivity, and morale of any healthcare organization.

In hospice and palliative care, our touchstone should extend beyond legalities and bioethics to provide enduring support — guiding us through constant business, organizational and regulatory changes, internal and external pressures, and the sensitive nature of our work.
Not only are we held accountable for our own actions, but we are also judged by the conduct of our peers — those who operate in the same field.

As such, it is essential that all hospice and palliative care organizations operate in a caring, ethical, and trustworthy manner in all facets of their clinical and business activities, seeking to uphold the highest levels of conduct. A strong organizational ethic helps to facilitate conversations between professional groups both within and outside of a hospice and palliative care organization.

NHPCO is committed to working with hospice and palliative care organizations to ensure these principles and guidelines are effectively understood and implemented in programs across the country. We believe they will help hospice and palliative care providers foster the highest possible ethical standards in serving the needs of their patients, their families and their communities.
HOW TO USE THESE PRINCIPLES AND GUIDELINES

There are a variety of ways in which these Principles and Guidelines can be used by the hospice and palliative care community. They can provide guidance at two different — but intersecting — levels:

- at the organizational level — both internally and externally;
- at state and national levels.

At the same time, however, these principles and guidelines are intended to be a living and vibrant set of guidelines for each organization and should be viewed as a roadmap for ongoing assessment and implementation of necessary changes. They are designed to be adapted, customized, and modified according to the unique characteristics of each hospice and palliative care organization. Note that regardless of the organization’s proprietary status, tax status or religious orientation, Board members, employees and volunteers are not exempt from inducement issues or other ethical and compliance concerns that are described in this document.

Each topic includes a Principle, its Intent, Guidelines for following the Principle, and Examples of actions or situations related to the principle that have been designated as “Optimal” or “Not Recommended”.

NHPCO hopes that the information provided will assist in decision-making that cultivates and deepens the trust placed in hospice and palliative care organizations.

Given its nature, this document should not be viewed as establishing standards of conduct or practice generally applicable to hospice or palliative care organizations, and its contents are not intended to be used by others for legal, regulatory or enforcement purposes.
Guidance at the Organizational Level

**Internally**

These Principles and Guidelines have been designated as an educational tool for all the individuals who comprise the organization — leadership, staff, and volunteers. They should be helpful in creating governing body and employee meetings and discussions concerning organizational ethics issues, more formal educational sessions, and policy formation and review. In addition, they can be used as a benchmark against which to gauge overall clinical and organizational ethics efforts.

The Principles and Guidelines will also help to develop an organizational structure and culture that meets both voluntary and mandatory standards promulgated by other institutions. Two increasingly common approaches are to develop a separate organizational ethics committee or to charge an existing ethics committee with organizational ethics issues.

**Externally**

The Principles and Guidelines are an excellent source of information for educating members of the community who come into contact with or can support the organization. They also offer a framework for relationships with other healthcare providers in the community — be they local, regional, state-wide or as part of a network. Hospice and palliative care organizations have much to learn from one another, and a sharing of best practices, policies, successes — and even failures — in the clinical and organizational ethics area will help fulfill organizational missions in a more complete way.

Guidance at State and National Levels

The Principles and Guidelines provide a helpful means through which the overall hospice and palliative care industry can actively ensure organizational standards meet the high standards the public expects. They can be used by state and national hospice and palliative care organizations to facilitate their efforts and further the trust relationships with other entities.

These Principles and Guidelines also will aid hospice and palliative care organizations — at all levels — to maintain an industry and regulatory environment which strengthens the trust placed in them by their stakeholders and enable them to offer services to everyone who is in need of hospice and palliative care.
THE NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION’S
ETHICAL PRINCIPLES

Members of the National Hospice and Palliative Care Organization should subscribe to and practice the following principles.

INTERNAL RELATIONS

A. Patient and Family

- **Admissions**
  Offer access to hospice and palliative care to all patients and their families in need of those services.

- **Care and Services**
  Provide patients and their families with the highest possible level of quality end-of-life care and services, while maintaining professional boundaries that respect their rights and privacy.

- **Conflicts of Interest**
  Avoid activities that conflict with the organization’s responsibilities to patients and their families.

- **Discontinuation of Care**
  Discontinue care only upon the voluntary consent of the patient, when the patient is no longer medically eligible, or when the organization cannot provide care without compromising the ethical or professional integrity, or the safety, of its employees.

- **Information Management, Confidentiality and Privacy**
  Respect and protect confidential information.

B. Employees and Volunteers

- **Employee and Volunteer Relations**
  Ensure that hospice and palliative care employees and volunteers are treated with respect and fairness, while supporting their ability to obtain the highest level of skill and expertise in their profession or role.

C. Governance

- **Governance**
  Adhere to governance structures that ensure the organization fulfills its mission and purpose.
EXTERIOR RELATIONS

A. Hospice Market (other hospices, suppliers, payers)

☐ External Collegial Relationships
  Work cooperatively with other healthcare providers, suppliers and payers to provide compassionate and competent end-of-life care.

B. Donors

☐ Development and Fundraising
  Be open and transparent in soliciting and accepting financial and/or in-kind support.

C. General Public

☐ Access
  Promote universal availability of comprehensive hospice and palliative care services, in diverse healthcare settings and with specific emphasis on reaching traditionally underserved populations.

☐ Marketing and Referrals
  Follow marketing and referral practices that promote compassionate, high-quality care for patients and their families.

☐ Public Information
  Develop and disseminate accurate, honest and timely information about hospice, palliative care and other end-of-life issues to local, state and national communities.

D. Society

☐ Research
  Support the advancement of knowledge to improve the provision, quality, and outcomes of hospice and palliative care.

Note: Due to the overlapping nature of external and internal relations, and to enable easier use of this document the following “Principles and Guidelines” are listed alphabetically by topic.
**PRINCIPLES AND GUIDELINES**

**ACCESS**

**Principle**
Promote universal availability of comprehensive hospice and palliative care services, in diverse healthcare settings and with specific emphasis on reaching traditionally underserved populations.

**Intent**
To expand the numbers and types of patients and their families who receive hospice and palliative care services; to reach out to patients with any life-limiting illnesses; to reach out to ethnic and minority communities which have not traditionally accessed hospice and palliative care; and to take steps to remove barriers to hospice and palliative care referral and admissions, despite financial risks and social challenges.

**Guidelines**
1. Review and eliminate practice patterns and organizational procedures that might impede or restrict access.
2. Provide access to care as broadly as possible within reasonable organizational constraints.
3. Offer respectful services to patients and families with diverse ethnic, cultural, and religious beliefs and attitudes toward death and dying.
4. Foster an organizational climate which is inclusive and appreciative of patients’ ethnic, cultural, religious, spiritual, economic and lifestyle diversity.
5. Project a welcoming message and image to diverse members of the community.
6. Remain current on research and national standards for palliative treatment of chronic, progressive and degenerative diseases.
7. Work with local physicians and community groups to inform the public about what services are offered by local hospice and palliative care programs.
8. Employ and train adequate numbers of staff and volunteers to care for patients of all ages and with a wide range of life-limiting diseases and conditions.
9. Collaborate with other providers for continuity of care as patients transition among providers and treatment approaches.

10. Commit to serve underserved patients to the extent possible, despite financial risks and social challenges.

**Examples**

**Optimal**

- Develop and communicate a plan of care that specifies the number of team visits and other services, according to patient/family needs, situations and available resources.
- Commit to providing access to all in the community in equitable numbers through responsible budgeting, fund-raising, and financial planning, with the governing body holding managers accountable for access and case mix goals.
- Communicate regularly with physicians through visits, mailings, newsletters, managed care networks, Web sites, and e-mail.
- Communicate with the media to clarify principles of quality end-of-life care, as well as clinical and financial aspects of hospice and palliative care, including those pertaining to the physician-patient relationship.
- Offer resources to healthcare professionals that foster better communication about hospice and palliative care with their patients.

**Not Recommended**

- Limit home health aide visits, social work visits or other services by rigid formulas, without consideration of patient needs and wishes.
- Restrict admissions for patients with non-cancer diagnoses.
- Restrict admissions for patients requiring expensive treatments.
- Oppose the creation of new hospice and palliative care programs in the area simply to protect business interests, if the current hospice and palliative care capacity is inadequate to meet patient demand and need.
ADMISSIONS

**Principle**
Offer access to hospice and palliative care to all patients and their families in need of those services.

**Intent**
To respond adequately and quickly in admitting patients that are medically eligible for hospice and palliative care and to conduct admissions consistent with patients’ and families’ best interests.

**Guidelines**
1. Admit all eligible patients, regardless of their ability to pay.
2. Ascertain and honor the wishes, concerns, priorities, and values of the patients and their families consistent with the law and the organization’s policies.
3. Support, affirm, and empower families as caregivers.
4. Consistently apply non-discriminatory admissions policies.
5. Admit patients in a timely manner, regardless of time of day or day of the week.
6. Refer to another provider when unable to adequately serve a patient.
7. Give patients and families accurate and easily understood information sufficient for truly informed consent.
8. Inform patients of their rights and responsibilities.
9. Assess community end-of-life needs and evaluate the organization’s ability and success at meeting them.
10. As appropriate, adapt services to evolving community needs.
11. Accept eligible patients transferred from another hospice or palliative care program.
Examples

Optimal

- Admit a patient who has exhausted all possible sources of funding for their care.
- Offer reasonable security to personnel serving high crime areas.
- Provide admission services on Saturdays, Sundays, evenings and holidays as appropriate.
- Accept patients who are receiving radiation or other high cost treatments, when the patient is otherwise eligible to receive hospice or palliative care services.

Not Recommended

- Delay in admitting a patient when another hospice and/or palliative care provider is available to admit the patient immediately.
- Delay a patient’s admission until the patient completes a course of palliative radiation and/or chemotherapy consistent with the organization’s treatment protocols for admitted patients.
CARE AND SERVICES

Principle
Provide patients and their families with the highest possible level of quality end-of-life care and services, while maintaining professional boundaries that respect their rights and privacy.

Intent
To ensure that patients and families receive the best possible care, regardless of their ability to pay, age, ethnicity, cultural and religious beliefs, social status, sexual orientation, attitudes toward death and dying, end-of-life disease, or condition.

Guidelines
1. Ensure that care and services are not diluted or diminished based on the patient’s ability to pay.
2. Employ and train adequate numbers of staff to care for patients regardless of age or end-of-life diseases and conditions.
3. Collaborate with other providers for continuity of care as patients transition between levels of care.
4. Ascertain and honor the wishes, preferences, concerns, priorities and values of the patients and their families consistent with the law and the organization’s values and policies.
5. Support, affirm and empower families as caregivers.
6. Consult experts when providing care to patients with conditions the staff has less experience in treating.
7. Give patients and families accurate and easily understood information regarding their condition and treatments.
8. Fully disclose information to patients and families regarding cost, services, and complaint policies, as well as any policies regarding discontinuation of hospice services.
9. Assume the responsibility to keep relationships with patients and families, and the bereaved after the death of a patient, on a professional level and maintain professional standards and boundaries.
10. Respect patient privacy and personal boundaries and do not enter into the patient’s family life and affairs any further than is required to meet the goals of the care plan.
Optimal

- Upon admission, review the services provided and associated costs to the patient.
- Ensure all members of the interdisciplinary team assess the patient within timelines required by the organization’s policies, with follow-up visits according to the plan of care.
- Respect cultural, ethnic, and religious beliefs of the patient and family.

Not Recommended

- Limit the type of medical equipment provided to a patient with no funding.
- Disregard the responsibility of maintaining professional boundaries by developing personal relationships with the patient and/or family.
- Discuss changes in care with family members without including the patient, when the patient is aware and able to make his/her own decisions.
- Accept a gift of higher value than is allowed by the organization’s policies. The policies should address any exceptions to the rules.
- Impose beliefs or values of a member of the hospice or palliative care team on the patient and/or family.
CONFLICTS OF INTEREST

Principle
Avoid activities that conflict with the organization’s responsibilities to patients and their families.

Intent
To uphold the fiduciary responsibility of the organization to protect the best interests of patients and families and the organization, without exploiting relationships with individuals, other organizations, or the community-at-large. This is accomplished by prohibiting conflict of interest or the appearance of conflict of interest and protecting vulnerable individuals from abuse of power motivated by personal or financial gain. This principle also serves to sustain and promote truth and trust in relationships that are essential to the provision of quality hospice and palliative care.

Guidelines
1. Ensure that hospice services are not diluted or diminished for financial reasons.
2. Do not use information gained through the course of the relationship with a patient or family member for organizational or personal gain or benefit.
3. Ensure that hospice and palliative care employees and volunteers do not use their position for personal or financial gain.
4. Published policies prohibit solicitation or gifts by employees and/or volunteers and limit the acceptance of gifts beyond a nominal value, taking into account appropriate cultural and ethnic considerations. The policies should address any exceptions to the rules.
5. Disclose the organization’s gift policy to patients and families at the time of admission.
6. Disclose and address all gifts of a nominal or greater value given at the expressed wish of the patient.
7. Do not give or accept gifts or services of value or monetary compensation in order to receive or make referrals.
8. Make and accept referrals solely in the best interest of the clients.
9. Take full responsibility for ensuring that the rights and dignity of patients, bereaved and their family members are respected and safeguarded.

10. Fully disclose information to patients and families regarding cost, services, and complaint policies, as well as any policies regarding discontinuation of hospice services.

11. Assume the responsibility to keep relationships with patients and families, and the bereaved after the death of a patient on a professional level and to maintain professional standards and boundaries.

12. Ensure that employees and others who report violations in fiduciary obligations and conflicts of interest are protected from any retaliatory actions by anyone in the organization.

13. Define in writing for employees inappropriate relationships of a business, social, professional, romantic, and sexual nature. Clearly articulate sanctions for such violations in hospice policies and procedures. Explain processes for registering a complaint with organization’s management team.

14. Adopt business policies and practices that comply with the Administration simplification requirements and standards of the Health Insurance Portability and Accountability Act (HIPAA) of 1996.

15. Adopt a formal compliance program as a mechanism to prevent fraud and abuse, provide for confidential reporting of compliance issues without fear of retribution or reprisal, strengthen operational quality, improve the quality of services, and contribute to reducing the cost of healthcare.

16. Have a process and format in place to deal with situations arising from conflicts based on ethical principles.
CONFLICTS OF INTEREST, CONT.

Examples

Optimal

◆ Avoid providing hands-on care to non-hospice residents in a long term care facility except in the case of an emergency.

◆ Refuse to trade stocks or securities based on “insider information” received from a patient or family member.

◆ Discuss a patient’s condition only with the patient, designated family member(s), and staff who “need to know” in order to ensure the best possible care.

Not Recommended

◆ Solicitation by an employee or volunteer to be remembered with money in a patient’s will.

◆ Moonlight (e.g., a hospice team member who is compensated privately by the patient/family to provide care for the hospice patient outside of the hospice plan of care) without the employer’s knowledge and/or to the detriment of the patient or family.

◆ Make an agreement with a long term care facility to supplement their staffing in exchange for referrals.
DEVELOPMENT AND FUNDRAISING

**Principle**
Be open and transparent in soliciting and accepting financial and/or in-kind support.

**Intent**
To honor and respect the intimate relationships hospices and palliative care organizations share with their patients and families and do not take advantage of their position and role(s) in soliciting and accepting support; to safeguard the integral role that they play within their communities.

**Guidelines**

1. Ensure that public support for hospice and palliative care organizations is truly voluntary and not the result of any undue influence.
2. Comply with the intent of the benefactors and donors supporting the hospice program.
3. Prohibit employees and volunteers from actively soliciting donations from patients and families who currently are receiving services.
4. Disclose clearly the sources and use of funds.
5. Make available, upon request, expenses involved in the fundraising process.
6. Publish and distribute, on a regular basis, a report or letter that includes critical information in the following areas:
   a. the organization’s board and key employee leadership;
   b. the vision, mission, and values of the organization;
   c. the core governance structure/members of the governing body;
   d. the organization’s critical programs and achievements;
   e. accurate and timely financial statements; and,
   f. a list of donors and their donations, with appropriate “anonymous” citations, in compliance with HIPAA regulations.
Examples

**Optimal**

- The organization clearly delineates or discloses its primary intent or function through the distribution of newsletters and other written materials, and by posting information online.
- The organization has a formal mechanism to account for and report on donor restricted funds (e.g.: money donated to purchase a specific item was used for that purpose).

**Not Recommended**

- Encourage volunteers to suggest that patients contribute to the organization’s current fundraising project.
- Provide preferential treatment or care to patients and families who are large donors to the organization.
PRINCIPLES AND GUIDELINES

DISCONTINUATION OF CARE

**Principle**
Discontinue care only upon the voluntary consent of the patient, when the patient is no longer medically eligible, or when the organization cannot provide care without compromising the ethical or professional integrity, or the safety, of its employees.

**Intent**
To ensure that all reasonable efforts are made to provide compassionate and quality care to patients and their families, to meet the patient’s plan of care, and to promote the values and philosophy of quality hospice and palliative care. There are three means in which patient care may be discontinued: withdrawal, transfer or discharge.

**Guidelines**
1. Fully disclose to patients and families information about policies regarding discontinuation of services.
2. Apply discharge criteria fairly and consistently, and have conflict resolution and appeals processes in place.
3. Do not abandon a hospice and palliative care patient once care has been initiated.
4. Honor patient decisions to withdraw voluntarily from hospice and palliative care without coercion from any employee or volunteer.
5. Ensure that, if a discharge decision is made, the organization provides appropriate referral information to other supportive services, and facilitates an orderly transition and continuity of care.
6. Prior to a discharge decision, the organization must facilitate a dialogue with the patient, the team and/or family or caregivers.
7. Discontinuation of care should not be based on a single incident, such as an emergency room visit without prior authorization from the hospice.
8. Do not encourage the discontinuation of care or revocation of a benefit in a way that compromises the rights or the voluntary nature of the patient’s choice.
9. Do not discharge a patient solely due to the cost of providing their care.
DISCONTINUATION OF CARE, CONT.

**Examples**

**Optimal**
- Consider discontinuing patient care if in the patient’s home environment there is a significant danger (e.g., animals, weapons) that poses a threat to patient/employee safety and the owner cannot or will not take action to correct the situation.
- After exhausting efforts to address the problem, discontinue care due to abuse or harassment of employees or volunteers by the patient or family members.

**Not Recommended**
- Discontinue care due to a perceived threat or danger without exhausting efforts to address the obstacle to safe caregiving.
- Discontinue care due to anticipated or realized expense of care.
- Discontinue care because one of the patient’s family members is a drug abuser.
- Discontinue care because there is a question about whether the patient has hospice coverage through his or her insurance plan.
EMPLOYEE AND VOLUNTEER RELATIONS

**Principle**

Ensure that hospice and palliative care employees and volunteers are treated with respect and fairness, while supporting their ability to obtain the highest level of skill and expertise in their profession or role.

**Intent**

To ensure that the organization does everything possible to support employees and volunteers in their ability to deliver compassionate, quality care.

**Guidelines**

1. Recruit, select, orient, educate, and evaluate each employee and volunteer to ensure proficiency and excellence based on identified job requirements.
2. Strive continually to raise the overall level of skill, expertise, and competency of employees and volunteers.
3. Seek to provide a safe, clean, and pleasant workplace.
4. Respect and be sensitive to the ethnic, cultural, religious, spiritual, and lifestyle diversity of employees and volunteers.
5. Protect against discrimination and/or harassment of employees and volunteers.
6. Support, affirm, and empower employees and volunteers in the work that they do.
7. Acknowledge the unique stressors inherent in providing hospice and palliative care and provide access to ongoing support for all employees and volunteers.
8. Ensure that contracted providers are properly trained and qualified, and that they provide care consistent with the values and philosophy of hospice and palliative care.
9. Foster an appropriately empowering and collaborative atmosphere to strengthen the interdisciplinary team concept and promote it throughout the organization.
10. Have a conflict resolution process in place and ensure it is followed.
11. Keep employees and volunteers appropriately informed of all critical information and communications.

12. Create a positive and supportive environment that fosters reporting of organizational, regulatory, compliance, and medical errors by employees and volunteers.

13. Reward employees and volunteers for suggesting ways to improve ethical responses to situations.

**Examples**

**Optimal**

- Provide both personal and professional growth opportunities for employees and volunteers.
- Provide counseling services for employees and volunteers when required, either internally or through the organization’s Employee Assistance Program (EAP).
- Ensure an effective and accessible means for employees and volunteers to safely raise concerns and questions.
- Provide employees and volunteers with a copy of the organization’s statements of mission, vision, values and ethical principles, and provide guidance on what type of behavior is expected in their respective positions.
- Structure employee and volunteer relations in order to foster an interdisciplinary team environment.

**Not Recommended**

- Establish a process for reporting and decreasing the risk of medical errors, but give little attention to reviewing and resolving known problems.
- Neglect employee requests for the organization to provide appropriate safety measures in patients’ homes (necessary security, needle disposal containers, etc.).
- Require employees or volunteers to work with patients and families before being oriented to their job responsibilities.
EXTERNAL COLLEGIAL RELATIONSHIPS

**Principle**
Work cooperatively with other healthcare providers, suppliers and payers to provide compassionate and competent end-of-life care.

**Intent**
To actively encourage civil, respectful and cooperative relationships within the community; to ensure that competitive practices do not interfere with quality end-of-life care; and to form collaborative relationships with other practitioners and healthcare providers.

**Guidelines**
1. Ensure the organization’s values and ethics are transparent in the community they serve.
2. Treat other agencies and organizations in the community with respect.
3. Recognize and respect the vital role of other healthcare organizations.
4. Use appropriate forums to actively pursue improvements in end-of-life care.
5. Maintain the highest professional standards and clearly disclose the existence of all relevant business and professional relationships with other organizations.
6. Share best practices with other healthcare providers.
7. Do not disparage other hospice and palliative care or healthcare organizations.
8. Work to educate others within the healthcare community to ensure those medically eligible for hospice and palliative care services receive them in a timely fashion.
9. Support the creation of community-wide, end-of-life continuous quality improvement initiatives.
10. Honestly and conscientiously cooperate with other agencies in providing information about referrals and to ensure that comprehensive services are provided seamlessly to patients and families.
11. Assess community end-of-life needs and evaluate the organization’s ability and success at meeting them.
12. Adapt services to evolving community needs.
13. Collaborate with other organizations to provide consumer education about end-of-life issues.

Examples

Optimal

◆ Use external benchmarking to compare quality indicators with other hospice and palliative care organizations.

◆ If a hospice perceives or hears of a problem occurring in another hospice, the first hospice should contact the second in order to report what it has heard and to help improve the situation. If this effort does not result in improvement, the organization may consider contacting the licensing body to lodge a complaint.

Not Recommended

◆ Delay responding to requests for assistance from local healthcare providers who may not have state-of-the-art pain management capabilities.

◆ Tell patients that another doctor or hospice and palliative care provider is inferior or sub-standard.
PRINCIPLES AND GUIDELINES

GOVERNANCE

**Principle**
Adhere to governance structures that ensure the organization fulfills its mission and purpose.

**Intent**
To govern effectively toward the successful achievement of an organization’s mission and to take responsibility for creating, maintaining, and improving an environment in which compassionate, quality care is provided to patients and their families.

**Guidelines**
1. Preserve the core purpose and mission of the organization, regardless of its business form or organizational structure.
2. Establish and maintain a governing body has complete responsibility for the organization including the establishment of a mission, purpose, and policies.
3. Ensure the governing body understands and upholds its fiduciary obligations.
4. Develop mechanisms whereby all perceived ethical issues can be identified, evaluated and resolved.
5. Develop mechanisms for addressing ethical issues and educating key stakeholders in their practical application.
6. Ensure that the governance system takes into account and builds upon the strengths and opinions of hospice and palliative care employees and volunteers.
7. Consistently and visibly respect diversity in all forms.
8. Lead efforts to ensure access to hospice and palliative care for all people facing the end of life.
9. Ensure that the selection, orientation, education, and evaluation of employees and volunteers are based on competency and willingness to execute job requirements.
10. Support, affirm, and empower employees and volunteers in the delivery of care and services.
11. Recognize the extraordinary stressors inherent in hospice and palliative care work and provide ongoing access to support for employees and volunteers.

12. Ensure that contracted providers are properly trained and qualified to provide care consistent with the values and philosophy of hospice and palliative care.

13. Promote a culture of adherence to the highest standards of performance and continuous improvement.

14. Develop and monitor a system for measuring compliance with ethical principles and guidelines that have been adopted by the organization.

15. Adopt a formal compliance program as a mechanism to prevent fraud and abuse, provide for confidential reporting of compliance issues without fear of retribution or reprisal, strengthen operational quality, improve the quality of services, and contribute to reducing the cost of healthcare.

**Examples**

**Optimal**

- Routinely assess the administrator’s performance and support professional development and improvement efforts.
- Routinely monitor the organization’s programs and services.

**Not Recommended**

- Infrequent self-assessment of performance by the governing body.
- Neglecting to establish and maintain a system that enables and encourages employees, volunteers, and contracted providers to report concerns about potential or real ethical violations, fraudulent behavior or obstacles to quality care.
**PRINCIPLES AND GUIDELINES**

**INFORMATION MANAGEMENT, CONFIDENTIALITY AND PRIVACY**

**Principle**
Respect and protect confidential information.

**Intent**
To ensure that all patient/family and organizational information is afforded adequate respect and protection.

**Guidelines**
1. Respect and protect the confidentiality of patients, families, caregivers, volunteers and co-workers.
2. Respond with sensitivity to any interruptions of privacy that are necessitated by the delivery of care.
3. Respect patient privacy and personal boundaries and do not enter into the patient’s family life and affairs any further than is required to meet the goals of the care plan.
4. Limit the sharing of information acquired to support the interdisciplinary plan of care to a “need to know” basis, and to the extent legally and prudently possible, to honor the patient’s wishes regarding this information.
5. Recognize the vulnerability and privacy needs of the patient and family, thus displaying extraordinary sensitivity in offering opportunities to promote hospice and palliative care.
6. Adopt business policies and practices that comply with the Administration simplification requirements and standards of the Health Insurance Portability and Accountability Act (HIPAA) of 1996.
Examples

Optimal
◆ Patient information is not given to another provider unless a proper release form has been submitted by the appropriate parties.
◆ Patient and financial records are confidential and securely stored in accordance with HIPAA standards.
◆ Information about staff and volunteers is not shared beyond the HR and supervisory roles.

Not Recommended
◆ Discuss patient and family information with a co-worker outside of the team space or in a common area of the office.
◆ Share confidential patient information with the patient’s neighbor, friend, or family member that the patient has not included on the signed release of information form.
MARKETING AND REFERRALS

Principle
Follow marketing and referral practices that promote compassionate, high-quality care for patients and their families.

Intent
To enhance public trust and access to hospice and palliative care; to serve the best interests of the patient and families; to base these relationships on the welfare of the patient/family/caregiver, not upon rewards and enticements; to share full and complete information and to support informed decision-making for and among patients and their families.

Guidelines
1. Disclose relevant business and financial relationships to patients and families so that they can make informed and knowledgeable decisions.
2. Ensure that marketing relationships do not limit the agency’s ability to disseminate information to patients and families.
3. Ensure that financial reimbursement is based on actual services provided.
4. Ensure that all staff incentives and bonuses are subject to appropriate checks and balances as required by the organization’s policies and applicable laws.
5. Be truthful, accurate, and transparent in public advertising and information dissemination.
Examples

**Optimal**

- The organization ensures that patients and families receive and understand information regarding care and services, as well as business and financial relationships. Although handing a patient a report or brochure about the organization is technically "disclosure", explaining the information is more patient-centered and prudent.

- If, for emotional and/or cognitive reasons, a family is unable to make a decision regarding hospice and palliative care services, the organization engages state and/or local social services to assist them in understanding their options and making a decision about which services would meet the needs of the patient.

- Acknowledge financial relationships with other providers during the intake and consent process.

- Participate in a voluntary coalition to promote the importance of end-of-life care planning with other health care providers in the community.

**Not Recommended**

- The organization participates in a contract that contains an "exclusive relationship" clause – i.e. a health plan agreement that says referrals cannot be made outside of the network.

- Ask newly bereaved family members to promote hospice services in advertisements.
PUBLIC INFORMATION

**Principle**
Develop and disseminate accurate, honest and timely information about hospice, palliative care and other end-of-life issues to local, state and national communities.

**Intent**
To create and distribute accurate and fair public information and education in a timely manner and to foster ongoing relationships based on trust.

**Guidelines**
1. Take a responsible and active role in the creation and dissemination of public information concerning hospice and palliative care.
2. Engage in dialogue about end-of-life issues in public forums.
3. Facilitate and promote consumer discussions regarding end-of-life care.
4. Serve on committees or in groups concerned with policy-making decisions which affect healthcare.
5. Encourage the inclusion of hospice and palliative care in all federal, state, and commercial healthcare plans.
6. Recognize the organization’s responsibility to reach out and make information available to all sectors of the community.
7. Fully disclose information regarding cost, services, complaint policies and policies regarding discontinuation of care.
8. Be prepared to deliver what the organization promises to the patient/family, and community.
9. Recognize the vulnerability and privacy needs of hospice and palliative care patients and families.
10. Design educational materials to maximize public understanding, and where appropriate, have these materials (or similarly appropriate materials) available in languages used within the community served by the organization.
Examples

Optimal

◆ The organization takes extreme care to avoid potentially misleading statements to any of its audiences.

Not Recommended

◆ The organization portrays itself as “preferred” or implies that there is a preferred relationship when this is not the case.

◆ Active patients and their families are recruited to participate in paid advertisements for an individual program.

◆ The organization uses market pressures to justify the use of practices that may undermine the integrity of hospice and palliative care or the trust placed in the organization by the public.
RESEARCH

**Principle**
Support the advancement of knowledge to improve the provision, quality and outcomes of hospice and palliative care.

**Intent**
To assist in developing knowledge, new understandings, and practices in the field through a process that maintains scientific and moral integrity; to offer patients, family members, and/or other research subjects the opportunity to participate in the research process to help improve practices related to hospice and palliative care; and to appropriately balance the pursuit of knowledge with the duty to protect patients, families, and other research subjects.

**Guidelines**
1. Thoroughly evaluate research proposals and similar cooperative arrangements to ensure that they conform to all appropriate regulations, and that they contain adequate protections for patients, families and other research subjects.
2. Ensure patients and families understand that research is not necessarily therapeutic and that election to participate is entirely voluntary.
3. Educate employees in the proper methods and protocols regarding the conduct of research.
4. Have a meticulous process in place to thoroughly evaluate the research protocol before engaging in research projects.
5. Utilize an institutional review board (IRB) for all human subject research.
6. Review relevant research findings regularly to enhance the practice of hospice and palliative care.
7. Develop and utilize internal mechanisms for the systematic collection of data within the organization for improving the quality of hospice and palliative care, including outcome measures that track the organization’s actual performance.
8. Establish mechanisms for sharing research findings with others to advance the provision of hospice and palliative care.
Examples

Optimal
◆ Hospice and palliative care employees ensure that patients understand the research project and provide informed consent prior to participating in the study.
◆ Patient names and identifiers are kept confidential and research records are secured in all phases of a research project.
◆ Surrogate decisions for research participation are clearly and appropriately documented.

Not Recommended
◆ Human subject research on patients receiving hospice and/or palliative care is begun before researchers secure Institutional Review Board approval.
◆ Research findings are shared with only a few of the organization’s closest associates, instead of the healthcare community at large.
GLOSSARY OF KEY TERMS

Admission:
The formal process of accepting responsibility to care for a patient.

Autonomy:
From the Greek word meaning “self-governance,” an ethical principle enjoining respect for the capacity of the individual to form and act upon his/her own plans, aspirations, and preferences.

Beneficence:
From the Latin word for “doing good,” an ethical principle stating the duty to do good both individually and for all.

Best Interest:
A standard of decision-making for people who are not able to make decisions for themselves (e.g. a person in a coma). The best interest standard is based on what a reasonable person would want done in a given situation.

Confidentiality:
The duty to respect privacy of information and action.

Guidelines:
Generalized models and methods that have proven to be useful in previous projects. Due to their general nature, guidelines do not always demand strict adherence, but do offer direction. If one finds reasonable cause, not following the guidelines can sometimes be appropriate.

IRB (Institutional Review Board):
An independent, peer review panel that makes recommendations for the acceptability of research intending to use hospice and palliative care patients, employees or others as subjects.

Justice:
An ethical principle stating the duty to treat all fairly, distributing the risks and benefits equally.

Leadership:
The senior management of a hospice and palliative care organization. This could be the CEO, president, members of the board, senior staff or other persons who have financial and executive decision capabilities.
Nominal Value:
An agreed-upon maximum value a gift may have. Most organizations define a gift under a specific monetary value (i.e. $25, $50 or $100) as a gift of nominal value. Employees, volunteers, and board members usually are required to declare a gift given to them.

Nonmaleficence:
An ethical principle stating the duty to cause no harm, both individually and for all.

Organization:
Any intentionally organized group of individuals who share a common goal. Throughout the NHPCO Principles and Guidelines, organization refers to both hospice and palliative care organizations and institutions.

Organizational Ethics:
Standards of conduct concerning how hospice and palliative care organizations, employees and volunteers should behave based on guidelines derived from core principles.

Principles:
Like guidelines, principles are generalized models or templates for behavior. The difference between a principle and a guideline is that principles represent a strong commitment to a certain set of values or ideas that may be enforced by the organization, whereas guidelines do not always demand strict adherence.

Quality of Life:
The nature of a person's experience in living. It does not imply that life is without inherent value or dignity.

Respect (for persons):
The duty to honor others, their rights, and their responsibilities. Showing respect for others implies that they are not treated as a mere means to an end.

Transparent:
Organizations can be called transparent if they have open and fair systems for informing stakeholders of their activities and decisions.
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**Advance Directives/Advance Care Planning**


NHPCO’s Caring Connections: provides free advance directive documents and instructions for each state. [www.caringinfo.org](http://www.caringinfo.org)


**Artificial Nutrition and Hydration**


RESOURCES


**Children’s Issues**


**Communication**


**Do Not Resuscitate (DNR)**


**Decision Making**


End-of-Life Medical Management/End-of-Life Care


Steinhauser, K.E., et al. (2000). In search of a good death: Observations of patients, families, and providers. Ann Int Med, 132, 825-832.


Ethics Basics/Foundations


### Ethics Consultation/Ethics Committees


### Futility


Hope/Spirituality/Miracles


Hospice


Informed Consent


Intensive Care Unit Care at the End of Life


Long Term Care


Organ Donation after Cardiac Death

Palliative/Respite Sedation


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Patient Preferences


Physician Assisted Suicide


Lynn, J. (1999). Debates of physician-assisted suicide are a barrier to real reforms in caring for patients. *WJM,* 171, 281.


Prognosis

Tanneberger, S., Malavasi, I., Mariano, P., Pannuti, F. & Strocchi E., Planning Palliative or Terminal Care: The Dilemma of Doctors’ Prognoses in Terminally Ill Cancer Patients *Annals of Oncology,* 13, 1320-1322. [http://annonc.oxfordjournals.org/cgi/content/full/13/8/1320-a](http://annonc.oxfordjournals.org/cgi/content/full/13/8/1320-a)

Regulatory Considerations


Research With Patients Who Are Terminally Ill


Symptom Management

Beth Israel University Medical Center. Palliative Care. Ethical/Legal Issues. Ethics and Law. [http://www.stoppain.org/palliative_care/content/ethical/law.asp](http://www.stoppain.org/palliative_care/content/ethical/law.asp)


Withdrawing/Withholding Life-Prolonging Therapies


Other Resources


NHPCO’s Ethics Committee
http://www.nhpco.org/i4a/pages/index.cfm?pageid=4701

NHPCO’s Managed Care Task Force
http://www.nhpco.org/i4a/pages/index.cfm?pageid=3293

NHPCO’s Regulatory Subcommittee
http://www.nhpco.org/i4a/pages/index.cfm?pageid=4705

NHPCO Technical Assistance Resources

◆ Standards of Practice
◆ Ethical Principles: Guidelines for Hospice and Palliative Care Clinical and Organizational Conduct
 http://www.nhpco.org/i4a/pages/index.cfm?pageid=3273&openpage=3273
