

ORIENTATION MANUAL

Self-Study Program for Hospice Employees

OVERVIEW:

This manual addresses core concepts and topics known to assist you in your work within hospice and palliative care, especially within a rural setting. It is intended as a guide to direct you to other resources that will supplement the information provided. Each discipline will require further reading, study and information. Check with your agency to find information specific to nursing, social work, volunteer work, therapy (physical, occupational, music, etc), and for clergy. Experiential learning will be a major component of hospice work as you attend IDT case management meetings, and through observation during site hospice site visits.

Resources and web sites are listed as the end of this document. Since web sites frequently change formats and information, we cannot be responsible for changes that occur once this document is placed on our website. We are listing these as current resources. These key websites will lead you to multiple resources about hospice and palliative care.

In addition, it is strongly suggested that a library of current books on hospice and palliative care be available to supplement the topics suggested in this Orientation Manual outline and to use as ready references. These books include:

1. American Academy of Hospice and Palliative Medicine (1999). *Hospice and Palliative Medicine: Core Curriculum and Review Syllabus*. Dubuque, Iowa: Kendall/Hunt Publishing Company
2. Andrews, M., & Boyle, J. (1999). *Transcultural Concepts in Nursing Care* (3rd Ed.). Philadelphia: Lippincott
3. Ferrell, B: (2001). *Textbook of Palliative Nursing*. Oxford University Press.
4. HPNA (1999) *Hospice and Palliative Nursing Practice Review* (3rd Ed) Kendall Hunt Press.
5. Lipson, J., Dibble, S., Minarik, P. (1996). *Culture & Nursing Care: A Pocket Guide*. UCSF School of Nursing Press.
6. McCaffery, M & Pasero, C. (1999). *Pain Clinical Manual* (2nd ED). St. Louis: Mosby.
7. Sheehan, D & Forman, W. (1996). *Hospice and Palliative Care: Concepts and Practice*. Boston: Jones and Bartlett Publishers.

8. Twycross, R. (1997). *Introducing Palliative Care* (3rd Ed.). Oxon, UK: Radcliffe Medical Press Ltd.
9. Weissman, D & Biernat, K. (1999). *Communication Teaching Modules for the End-of-Life Educator*. Milwaukee, Wisconsin: Medical College of Wisconsin.
10. Weissman, D. & Ambuel, B. (1999). *Improving End-of- Life Care: A Resource Guide for Physician Education*. (2nd Ed). Milwaukee, Wisconsin: Medical College of Wisconsin.

There are numerous journals that will have up-to-date research and information about palliative care and hospice.

GOAL

To assist Rural New Mexico Hospice staff in training and education of new personnel in similar and consistent methods across rural New Mexico sites. Each family and situation is unique.

OBJECTIVES

Upon completion of using this manual the hospice professional will have be introduced to the key components and topics for working within hospice and palliative care.

The hospice professional will have access to resources that can supplement and enhance your work experience and study of hospice and palliative care in rural areas.

SESSION OUTLINE

- I.** Welcome and Introduction
- II.** Overview of Orientation Process
- III.** Mission of Your Agency
- IV.** Introduction to Hospice/Palliative Medicine
 - a. Philosophy
 - b. History
 - c. Standards of Care
- V.** Concepts of Hospice/Palliative Care
 - a. Physical
 - b. Psychological
 - c. Spiritual (Body, Mind and Spirit)
- VI.** Role of Team Members in Hospice/Palliative Medicine
 - a. Medical Director
 - b. Patient Physician
 - c. RN
 - d. Social Worker
 - e. Pastoral Care
 - f. Certified Nurse Assistant (CAN)

- g. Family Member
- h. Community Member
- VII.** Introduction to Communication Issues of Hospice/Palliative Medicine
- VIII.** Specific Communication Skills
- IX.** The Healer Must be Healed - Importance of Self-Care
- X.** Exploring Personal Views
- XI.** Dealing with Stress
- XII.** Cultural Issues Related to Hospice/Palliative Care
- XIII.** Assessment of Pain – Role of Team Members
- XIV.** Pain Management
- XV.** Pain as the Fifth Vital Sign
- XVI.** Symptom Management
- XVII.** Psychosocial Issues
- XVIII.** Spirituality Issues
- XIX.** Grief and Bereavement
- XX.** Ethical and Legal Issues
- XXI.** Individual Disciplines
- XXII.** Helping People Understand the Health Care System Related to Hospice/Palliative Care
- XXIII.** Continuing Education
- XXIV.** Resources

ACTIVITIES

- Reading
- Interactive participation
- Discussion with agency staff
- Interactive participation/website

HOSPICE INTERDISCIPLINARY COMPETENCIES:

Competencies considered important to work in hospice and palliative care include:

- Be able to articulate hospice philosophy, goals and objectives with emphasis on the meaning of palliative care and the meaning of quality of life
- Demonstrate an understanding of your organization's communication system, means of personal support and continuing education processes
- Articulate basic ethical principles and your agencies approach to decision making from an organizational and clinical perspective
- Explain the Interdisciplinary Team (IDT) Case Management Process
- Outline the process of patient/family referral and admission
- Demonstrate an understanding of hospice and palliative nursing care
- Demonstrate an understanding of spiritual care within hospice and palliative care
- Demonstrate an understanding psychosocial care

- Discuss grief and bereavement issues related to hospice and palliative care
- Discuss the importance of accepting diversity in hospice and palliative care
- Discuss the importance and utilization of hospice volunteers
- Demonstrate appropriate death attendance and closure skills
- Articulate and demonstrate an understanding of providing and documenting patient care across settings, including reimbursement and regulatory issues
- Discuss the utilization and referral procedure for ancillary services
- Discuss the role of hospice in community outreach efforts and services
- Articulate the key components of communication in hospice and palliative care
- Articulate and practice self-care activities

I. Welcome and Introduction

1. Thank you for joining our hospice team. You may have years of experience with hospice settings and hospice care or you may be new to working with a hospice team. We are glad you are here. My experience is that people who come to work in hospice are caring, compassionate, loving and empathic individuals. Your purpose is ultimately to help this team help others, not to cure, but to heal. We will talk about the real meaning of healing later in this process. There is basic information for everyone to know and there are many areas of specific information for specific team members, such as the RNs, social workers, and therapists. Since we do work out of a team concept, knowing the role of each team member can keep the process running smoothly. Although some team members may be responsible for exact information, each team member has a responsibility to have a general understanding of hospice/palliative care concept and the potential needs of patient and family.
2. Introduce yourself to all team members. (Have each individual tell why they have chosen to work in hospice and a BRIEF story about their association with someone in pain or with the dying process.)

II. Overview of Orientation Process

1. Review the sections of the Manual and topics to be covered.
2. Review the section on Resources - this will be important to supplement information in the Manual.

III. Mission Statement

Review the Mission Statement for your agency and for the National Hospice/Palliative Care Association. **See:** National Hospice and Palliative Care Organization

1. Review Goals and Objectives for your agency

IV. Background and History of Hospice/Palliative Medicine

Resources:

American Academy of Hospice and Palliative Medicine (1999). *Hospice and Palliative Medicine: Core Curriculum and Review Syllabus*. Dubuque, Iowa: Kendall/Hunt Publishing Company

Weissman, D & Biernat, K. (1999). *Communication Teaching Modules for the End-of-Life Educator*. Milwaukee, Wisconsin: Medical College of Wisconsin.

1. Background and History of Hospice Versus Palliative Care
2. Review history of hospice
3. Philosophy of hospice and palliative care defined by World Health Organization (WHO). Palliative Care = the active total care of patients whose diseases are not responsive to curative treatment – life-limiting illnesses.

Hospice care generally provided during the latter segments of the continuum of care for patients with life-limiting illnesses.

4. Hospices in rural U.S. takes place where people live and work. Hospice agencies in rural areas often have limited access to medications and personnel.
See statistics on: <http://www.nhpco.org>
Click on *Stats/Research/Resources*

V. Concepts of Hospice/Palliative Care

Resources:

American Academy of Hospice and Palliative Medicine (1999). *Hospice and Palliative Medicine: Core Curriculum and Review Syllabus*. Dubuque, Iowa: Kendall/Hunt Publishing Company

Ferrell, B. (2001). *Textbook of Palliative Nursing*. Oxford University Press.

1. Individual aspects of hospice/palliative care include several components as a wholistic approach. Review each component.
 - a) Physical
 - b) Psychosocial
 - c) Spiritual
 - d) Standards of Care
 - e) Barriers to Hospice/Palliative Care

VI. Role of Team Members in Hospice/Palliative Care

Resources:

American Academy of Hospice and Palliative Medicine (1999). Hospice and Palliative Medicine: Core Curriculum and Review Syllabus. Dubuque, Iowa: Kendall/Hunt Publishing Company

Ferrell, B: (2001). Textbook of Palliative Nursing. Oxford University Press.

HPNA (1999) Hospice and Palliative Nursing Practice Review (3rd Ed) Kendall Hunt Press.

Twycross, R. (1997). Introducing Palliative Care (3rd Ed.). Oxon, UK: Radcliffe Medical Press Ltd.

1. Identify team members and their relationship to the hospice/palliative care process
2. Review the role of each team member known as the Interdisciplinary Team (IDT)
 - a) **Medical Director** - collaborates with all members of the IDT to ensure that all aspects of suffering are addressed.
 - b) **Patient physician** - may depend on Medical Director of Hospice, but important to maintain a relationship with the patient and family
 - c) **RN** - coordinates the patient's care, communicates with attending physicians and other members of the team, assesses the patient's and family's needs, and supervises care in the patient's home and other settings.
 - d) **Social Worker** - helps patients and families access community resources and provide counseling for death related issues, including communication problems, anticipatory grief, bereavement issues, and follow-up grief and bereavement.

- e) **Pastoral Care** (clergy, minister, rabbi, or religious minister). Clergy address spiritual and religious issues, coordinate and/ or provide spiritual interventions, and offer spiritual support for patient and family members.
- f) **Certified Nurse Assistant (C.N.A.)** - bathes patients, assists with activities of daily living, offers comfort measures, and reports changes in patient's and family's condition.
- g) **Family Members** - usually the primary caregivers
- h) **Community Members** – often serve as volunteers who provide respite care for family members and perform various tasks, such as grocery shopping, etc.

VII. Introduction to Communication Issues of Hospice/Palliative Medicine

Resources:

Andrews, M., & Boyle, J. (1999). *Transcultural Concepts in Nursing Care* (3rd Ed.). Philadelphia: Lippincott

Twycross, R. (1997). *Introducing Palliative Care* (3rd Ed.). Oxon, UK: Radcliffe Medical Press Ltd.

Weissman, D & Biernat, K. (1999). *Communication Teaching Modules for the End-of-Life Educator*. Milwaukee, Wisconsin: Medical College of Wisconsin.

Communication is crucial to effective treatment of patients in hospice and palliative care. Confidentiality is critical to developing trust with your patients and among team members. Issues must be discussed, but only within the realm of IDT meetings. Volunteers especially may be told information that can be disturbing. It is important to jot down questions or information that needs to be clarified when it can be done tactfully. Then have the questions answered or information provided at an IDT meeting.

1. Effective communication is the first step to successful hospice and palliative care. Clear compassionate communication is essential for an effective therapeutic doctor-patient-healthcare professional relationship.
2. Review the importance of adequate and effective communication between team members. You will have opportunities to participate in developing your communication skills by way of interactive exercises later at an in-service or IDT meeting.
3. Effective communication is a process of conveying information and ensuring the receiver understands the intended message.

4. Listening is critical to effective communication. When with a patient and or family write notes for referral to the proper team member. Be sure to follow up on questions that you may not be able to answer.

VIII. Specific Communication Skills

1. Review the various aspects of communication, including verbal, non-verbal, attitudes, beliefs, rituals, taboos, etc.
2. Review the importance of listening; find out how your agency provides for experiential methods in developing listening skills
3. Review Breaking Bad News – role each team member has in supporting, listening, responding, or supplementing information.
4. Review the barriers to effective communication and listening
5. Review information about conflict and how to handle anger, yours and the patients and the patient's family.

IX. The Healer Must be Healed – Importance of Self-Care

Resources:

This type of work is best done in a group setting. Check with your hospice agency to find out what is available to you.

- In-service sessions
- Workshops
- IDT Meetings
- Grieving Support Groups

1. Review ways to care for self (Check to see how your agency provides for opportunities to be involved in an imaging exercise; meditation; yoga stretches, message or other means of caring for self.) The importance of debriefing and talking about experiences and the grief process is critical for each team member and a process that each must go through.
2. Use of seminars and other reflective exercises on death can provide opportunities aimed at preparing health care providers for the care of dying patients and their families. Whether a new employee or one that is coming to work in hospice/palliative care from a closely related work setting, recognizing and working through one's personal views

about death and dying, and identifying your values toward palliative care versus curative care are fundamental to work within a hospice setting. If you are still dealing with personal issues around a death situation, divorce, multiple losses (loss of a job, financial losses etc.) it is extremely important to identify these factors and to work through the grief process.

X. Exploring Personal Views

Resources

This type of work is best done in a group setting. Check with your hospice agency to find out what is available to you.

1. Identify stages of death and dying: Denial, Rage and anger, Bargaining, Depression, and Acceptance.
2. Review your agency policies on pronouncement responsibilities, appropriate death attendance and closure skills.
3. Review phases in the Grief Process, Physical, Emotional, Social, and Spiritual – there are professional people to help you work through your own grief process.
4. Review indigenous beliefs about death and dying related to cultural beliefs. Agency personnel or local individuals may be able to help understand what the local beliefs include.

XI. Dealing with Stress

Resources:

Check with your agency to see what opportunities you have for handling stress in both your personal life and your work setting.

1. Review the ways for stress management.
2. Go over techniques for managing stress

XII. Cultural Issues Related to Hospice/Palliative Care

Numerous nursing books and many websites address cultural issues, especially related to death and dying.

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Depending on the section of the country, a variety of ethnic groups may live within rural areas. A rural culture, based on independence, autonomy, and self-care is a facet of culture often neglected. Remember that culture goes beyond ethnic groups.

1. Review as many written materials as you can and find local people to talk with to discuss the beliefs relevant to your area. These beliefs can vary from area to area even within a state.
2. Review Hispanic beliefs about dying
3. Review Navajo beliefs about dying
4. Review issues related to Native American beliefs in general. (Beliefs vary between Pueblos, Nations, Reservations, Plains Indians, Urban Indians, etc.)
5. Discuss beliefs of other ethnic groups in New Mexico, or your particular area of the country.

XIII. Assessment of Pain - Role of Team Members**Resources:**

McCaffery, M & Pasero, C. (1999). Pain Clinical Manual (2nd ED). St. Louis: Mosby.

Sheehan, D & Forman, W. (1996). Hospice and Palliative Care: Concepts and Practice. Boston: Jones and Bartlett Publishers.

Websites:

<http://www.growthhouse.org>

<http://prc.coh.org>

1. Assessment of pain is critical – often it is a volunteer or health care aide who has the most contact with a patient and begins to hear the terms used by the patient for describing pain. This information is to be relayed to proper team members.
2. Understanding the pathophysiology of pain varies for each discipline on the hospice team; however, everyone on the team can have basic knowledge about the pain process at levels that can be understood.

3. Review definitions of pain
4. Review the implications of unrelieved pain
5. Cover concept of total pain - physical, psychological, spiritual, mental, and social domains.

XIV. Pain Management

Resources:

McCaffery, M & Pasero, C. (1999). Pain Clinical Manual (2nd ED). St. Louis: Mosby.

Sheehan, D & Forman, W. (1996). Hospice and Palliative Care: Concepts and Practice. Boston: Jones and Bartlett Publishers.

Websites:

<http://www.growthhouse.org>

<http://prc.coh.org>

plus information from your hospice agency; workshops, in-service.

Pain management is not only handled through administration of pain medications, but also through other methods of pain relief, including alternative methods.

1. Review pain management for your level of work
2. Review alternative methods of pain relief
3. Review barriers to effective pain management
4. Review components of pain assessment and role of each team member in assessment and management of pain.

XV. Pain as the Fifth Vital Sign

Resources:

<http://nmruralhospice.unm.edu>

1. Introduce the New Mexico Rural Hospice Network materials on pain management - use as reference for discussion.

2. Review any agency materials related to policies, procedures, and your agency tools for pain assessment and pain management.

XVI. Symptom Management

Resources:

HPNA (1999) Hospice and Palliative Nursing Practice Review (3rd Ed) Kendall Hunt Press.

Wrede-Seaman, L. (1999). Symptom Management Algorithms: A Handbook for Palliative Care (2nd Ed) Intellicard

websites

<http://www.growthhouse.org>

1. Review the evaluation and management of general non-pain symptoms.
2. Review the various organs and evaluation and management of symptoms specific to each.
3. review the role of each team member and their responsibility of management of symptoms

XVII. Psychosocial Issues

Resources:

Ferrell, B: (2001). Textbook of Palliative Nursing. Oxford University Press.

1. Review psychosocial issues associated with hospice and palliative care.
2. Health beliefs
3. Place of suffering and contributors of suffering
4. Beliefs; past experiences; conflict (dealing with anger); role function; impairment; culture; spiritual and existential concerns; loss of independence and control; sexuality and intimacy.
5. Quality of life

6. Strategies for coping with uncertainty.
7. Psychological aspects of chronic and terminal illness.
8. Care of the relatives

XVIII. Spirituality Issues

Resources:

Lipson, J., Dibble, S., Minarik, P. (1996). Culture & Nursing Care: A Pocket Guide. UCSF School of Nursing Press.

Last Acts <http://www.lastacts.org>

1. Explore personal beliefs about spirituality – Just as personal beliefs and values regarding death and dying are important to care of your patients, so too are your beliefs about spirituality and religious rituals.
2. Review differences between religiosity and spirituality
3. Identify different cultural beliefs related to spirituality.
4. Review the indicators of spiritual suffering and pain.
5. Review the impact of personal beliefs in the work setting of hospice and palliative care.

XIX. Grief and Bereavement

Resources:

Compassion in Dying – <http://compassionindying.org>

Growth House – <http://growthhouse.org>

Last Acts – <http://lastacts.org>

1. Review the grief and bereavement process: Grief is defined “as a person’s emotional response to the event of losing the “state of mental and physical pain that is experienced when the loss of a significant object, person, or part of self is realized.”
2. Review information about anticipated grief. Ask how your agency can help you work through issues you may have with anticipated grief.

3. Review information about complicated grief. Ask how your agency can help you understand and work through any issues you may have or that your patient and family may have regarding complicated grief.
4. Review the role of each team member in the bereavement process
5. Review your specific role and duties in helping families through the bereavement process.

XX. Ethical and Legal Issues

Resources:

Aging With Dignity <http://www.agingwithdignity.org>

1. Ethical Principles
 - a) Beneficence
 - b) Nonmaleficence
 - c) Autonomy
 - d) Justice
2. Decision-Making Capacity
3. Advanced Directives - Five wishes
4. Informed Consent
5. Withholding and withdrawing life-sustaining treatment
6. Futility
7. Do Not Resuscitate
8. Managing the Death Event

XXI. Individual Disciplines

1. Identify resources for each discipline
2. Review the specifics of disciplines according to new personnel, nursing, social work, therapists, clergy, volunteers, pharmacists, etc.

XXII. Helping People Understand the Health Care System Related to Hospice/Palliative Care

Resources:

National Hospice Organization. (1998) Hospice Care: A Physician's Guide. NHO: Arlington, VA

Medicare Hospice Benefit Website:

<http://www.hospiceinfo.org/index.cfm?webURL=/public/articles/index.cfm?cat=2>

1. Financing Hospice and Palliative Medicine
2. The Medicare Hospice Benefit
3. Reimbursement for hospice/palliative care

XXIII. Continuing Education

Find out how and where continuing education can take place within your agency.

We hope this Orientation Manual has been a resource for you to continue your study of hospice and palliative care. There is so much information that cannot be included in this process due to limited space. Please refer to Betty Ferrell's City of Hope <http://mayday.coh.org/> and other websites for a more intensive listing of resources.

XXIV. Resources -Website/Internet Resources

1. Aging With Dignity <http://www.agingwithdignity.org>
2. American Academy of Hospice and Palliative Medicine <http://www.aahpm.org>
3. Association of Oncology Social Work (AOSW) <http://www.aosw.org>
4. Center to Improve Care of the Dying <http://www.gwu.edu/~cicd>
5. End of Life Physician Education Resource Center (EPEC) <http://www.eperc.mcw.edu>
6. City of Hope/Palliative Care Resource Center <http://prc.coh.org>
7. Compassion in Dying <http://compassionindying.org>
8. Growth House <http://www.growthhouse.org>

9. Hospice and Palliative Nurses Association <http://www.HPNA.org>
10. Last Acts <http://www.lastacts.org>
11. National Hospice and Palliative Care Organization
<http://www.nhpco.org>
12. New Mexico Rural Hospice <http://nmruralhospice.unm.edu>
13. Wisconsin Cancer Pain Initiative <http://www.wisc.edu/wcpi>