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# Introduction to Hospice

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## Hospice Direct Care Volunteer Training – Course Objectives

Tufts Medicine Care at Home *Hospice Volunteer Training Program* has been designed to provide the participants with an in-depth understanding of how hospice can help the dying patient and his/her family, while fostering self-awareness about your own feelings and attitudes toward death and loss. By the conclusion of this course, you will be able to:

- Understand and articulate Hospice philosophy, including palliative care, pain control, and the team approach to care.
- Serve as an empathic listener and effective communicator.
- Understand and abide by Tufts Medicine Care at Home’s policies regarding the volunteer role, interdisciplinary team participation, and documentation.
- Articulate personal feelings about death and dying.
- Respond appropriately to the patient’s and family’s physical, psychosocial, and spiritual needs.

In addition to attending training sessions, participants are expected to read the *Hospice Volunteer Training Manual*, work on the homework assignments, and participate in group interactions. We ask you to turn in evaluation forms following each module; this provides us with helpful feedback for future training regarding course content, exercises, films, and presenters.

## The Hospice Movement

The word *hospice* stems from the Latin word *hospitium*, meaning *guesthouse*. It was originally used to describe a place of shelter for weary and sick travelers returning from religious pilgrimages. Over time, the word *hospice* gave way to more modern words, such as *hostel*, *hospital*, and *hospitality*. Essential in the meaning of *hospice* is the Latin root *hospes*, “the mutual caring of people for one another.”

The concept of hospice as we now know it originated in the 1960s with Dr. Cicely Saunders. Dr. Saunders saw the need for change from the medical model of treatment, where the needs of terminally ill patients were ignored once curative options were exhausted. She is quoted as saying, “There is never *nothing* more that can be done.” Dr. Saunders established St. Christopher’s Hospice in London, England, with the goal of keeping patients active, alert, and in charge of decisions about their own care for as long as possible. St. Christopher's organized a team approach to professional caregiving, and her program was the first to use modern pain management techniques to compassionately care for the dying.



Dr. Saunders introduced the idea of specialized care for the dying to the United States during a 1963 visit to Yale University. Dr. Saunders' lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after symptom control care. Also attending the lecture was Florence Ward, Dean of the Yale School of Nursing. Dean Ward later went to work with Dr. Saunderson's at St. Christopher's, and was, in turn, instrumental in developing the hospice movement in the United States.

Also paramount to the hospice movement was Dr. Elisabeth Kubler-Ross, and her book *On Death and Dying*, published in 1969. In this book, Kubler-Ross argued that patients should have a choice of receiving care at home instead of in a medical setting and should have the ability to participate in the decisions that affect their life. She identified what is now commonly accepted as the five psychological stages of grief many terminally ill patients experience (denial, anger, bargaining, depression, and acceptance). The book became an international best seller.

The first hospice in the United States was established in New Haven, Connecticut, in 1974, the same year that the first hospice legislation was introduced to provide federal funds for hospice programs. While legislation was not enacted that year, hospices began forming around the country, mostly utilizing a grass-root, voluntary staff.

In 1986, the provisional Medicare Hospice Benefit was made permanent by Congress. States across this country were given the option of including hospice in their Medicaid programs, making hospice care an option for terminally ill nursing home residents. As of 2006, hospice programs cared for 965,000 people enrolled in Medicare,<sup>1</sup> and nearly 1.4 million people in the United States in 2007<sup>2</sup>. As of 2009, the number of hospice volunteers continues to grow with a record 550,000 people serving as volunteers.

Today there are more than 8,796 hospice programs in the United States.<sup>3</sup>

## Introduction to Tufts Medicine Care at Home

Tufts Medicine Care at Home, the trusted name in the end-of-life care for more than 30 years, is one of the most respected not-for-profit hospices in the region. Our multidisciplinary team of physicians, nurses, counselors, home health aides, and volunteers work together to provide patients and their families with expert clinical care and support with compassion, commitment and the highest standards of excellence. Founded in 1980, Tufts Medicine Care at Home provides skilled nursing, pain control, symptom management and personal care for patients, as well as grief and

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<sup>1</sup> Figure from the Centers for Medicare & Medicaid Services (CMS).

<sup>2</sup> Figure from the National Hospice and Palliative Care Organization (NHPCO).

<sup>3</sup> History of Hospice information gathered from [www.hospicefoundation.org](http://www.hospicefoundation.org), and [www.nhpco.org](http://www.nhpco.org)



bereavement counseling and supportive services for families. In addition, specially trained volunteers provide a wide variety of services for the patient and the family.

In June 2009, Merrimack Valley Hospice opened the High Pointe House, the hospice and palliative care residence of Merrimack Valley Hospice and York Hospital Hospice. Located at 360 North Avenue in Haverhill, Massachusetts, HPH provides end-of-life care for patients whose pain and other symptoms can no longer be managed at home. HPH contains 21 private suites for patients and space to accommodate visitors who are welcome 24 hours a day. High Pointe House is the only hospice residence in the region licensed to care for children.

In 2018, with Wellforce of Burlington the parent company of Tufts Medicine acquired Merrimack Valley Hospice.

## Hospice Philosophy

As serious illness progresses, people often hear that there is nothing more that can be done. That is when hospice finds so much to do; not to cure, but to enhance the quality of life through care and comfort. Hospice focuses on this final season of life by adding “life” to a patient’s remaining days by making each moment of life as comfortable and as meaningful as possible.

Our highly skilled and dedicated team understands that caring for a hospice patient does not begin and end with treating the patient’s illness. Rather, our philosophy of care is to provide physical, emotional, and spiritual comfort to patients and their families.

Hospice is a choice for those facing serious life-threatening illness and loss. More and more people are choosing hospice because it returns a sense of control to them – by empowering them to choose how and where they wish to spend their remaining days and by assisting them to come to terms with death. Our wish is to help those with life-limiting illness find comfort and hope in each and every day of their remaining life...hope for time with loved ones, hope to get affairs in order, hope for life closure, hope for a peaceful death, hope for loved ones to “process loss” and be “okay,” and hope to be remembered. At the same time, we help families live through this difficult time by providing needed support and understanding.

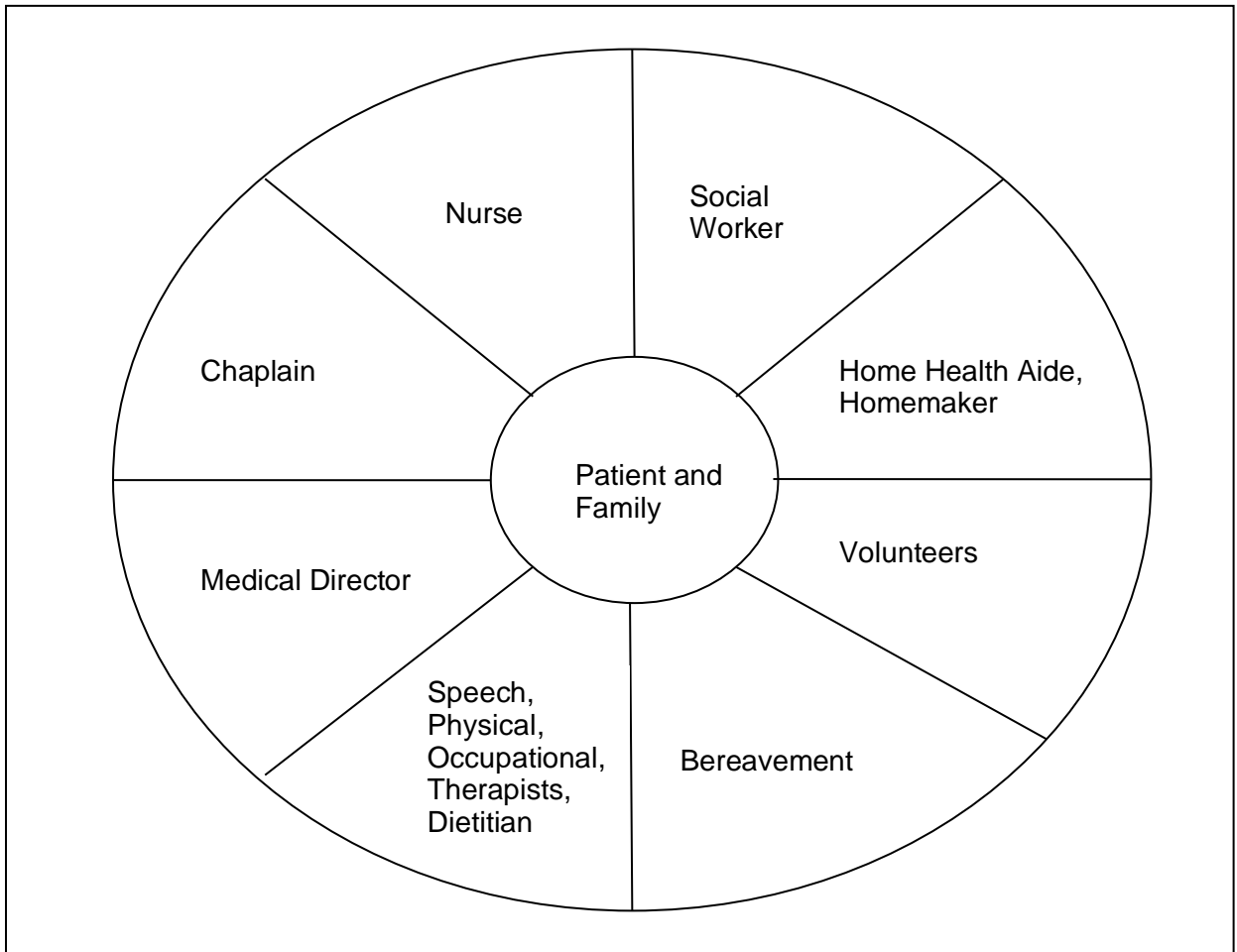
## Criteria for Admission to Hospice

Tufts Medicine Care at Home is available to all residents within our service area and facilities in which we serve. All patients meeting our admission criteria are admitted to our program, regardless of ability to pay. The patient must be in the advanced stages of a terminal illness. Therapies are no longer utilized for curing or eradication of the patient’s disease process. Palliative therapies will be used to control defined signs and symptoms which result from the disease. The Medicare Hospice benefit requires that the referring physician estimates that the patient’s life expectancy to be six months or less; this is co-certified by the hospice Medical Director. The patient and family should know the expected outcome of the disease, and together with their attending physician, agree that Hospice services are desired. There must also be a competent care giver (family, friend, paid care giver) willing to assume responsibility for the patient’s care if the patient is going to live at home. This will be addressed also in the nursing portion of the training.



In order to receive Hospice care over time, the patient must continue to experience a decline in condition within a certification period; there are initially two 90-day certification periods, (followed by 60 day recertifications thereafter). The Hospice Medical Director then submits a recertification notice to Medicare, saying that the patient continues to meet the criterion for hospice. Patients have been known to come off of hospice as well, when the criteria for meeting the certification changes, and there has been marked improvement.

An Interdisciplinary Team Approach to Care



Our hospice team is made up of individuals with diverse skills, experiences, and a true sense of commitment to patients and families. Those who work in hospice believe that qualities such as competency, empathy, warmth, and caring are key when choosing someone to be a team member. Together with the patient and family, the team develops an individualized plan of care, focusing on quality of life, care and comfort, pain management and symptom control. Although team members bring to the patient different skills and strengths, they are united for one purpose – to help the patient and family find comfort and peace. Note that the inclusive focus on both patient and family differs from a medical/non-palliative model, where the patient is the only focus.



The hospice interdisciplinary team is composed of the following:

**Medical Director:** The Hospice Medical Director serves at the head of the Interdisciplinary Team that provides direct service to the patient and family. The Medical Director communicates on an “as needed” basis with the patient’s primary physician, as do the nurses, to assure the highest quality of care.

**Nursing:** The hospice registered nurses (RNs) provide case management and are experienced in caring for patients living with life-threatening illness. They have special skills in the areas of pain and symptom management, providing skilled care, coordination with patient/family/ physicians and other medical personnel, education of the patient and caregivers. The nurses are skilled in family dynamics and supportive counseling, as well as nursing, physical and psychosocial assessment. The nurses serve as teachers in many ways, helping the patient and family to learn physical comfort measures, medication guidelines, and other necessary procedures. The nurses are available 24 hours a day, seven days a week to assist the patient with pain and symptom control, facilitate medication refills, and oversee other important changes in the patient’s condition. It is the nurse who officially pronounces that a patient has died. You will learn more about the services that the nurse renders in the chapter on Care and Comfort.

**Social Worker:** The Social Workers work closely with the patient and family to provide a supportive home care system to ensure safety, comfort, and attention to needs and concerns. Some of their responsibilities include connecting the patient and family with community agencies, determining eligibility for local and state assistance programs, addressing personal, emotional, financial, insurance, and care planning issues through individual and family counseling. The Social Worker helps the patient and family sort through the many questions and feelings they may have about living with a life-threatening illness (“Is it normal to feel so overwhelmed?” “Where can I find extra help for care at home?” “How do I help my family live with these changes?” etc.) The Social Worker provides information concerning advanced directives, health care proxy, or discussion about the Comfort Care/Do Not Resuscitate (DNR) process form. It should be noted that the Social Worker’s perspective is one of affirming the patient’s and family’s strengths and resources and advocating as needed. You will learn more about the role of the Social Worker in the chapter on Psychosocial Dynamics of Death and Dying as well as Family Dynamics.

**Chaplain:** End of life has been described by some as a spiritual event with medical implications. For many, this time reopens questions about the meaning of life and final wishes. The Chaplain, who is trained in theology, can be a companion or resource in this search for ultimate meaning for both the patient and family. Often there are many questions posed that, although seemingly unanswerable, deserve exploration – for example “Why me?” or “Why now?” The Chaplain can listen compassionately to these questions, as well as the patient’s and family’s needs and challenges, and provide spiritual support. The Chaplain can assist with (re)connection to the religious community, arrange for a music environment or hymns, assist in funeral or memorial service planning, and allow the patient to define his/her need for spiritual support. You will learn more about the service that the Chaplain provides in the chapter on Concepts of Death, Dying and Spirituality.

**Home Health Aide:** The Hospice Aides are often the members of the team who spend the most time with the patient. According to the plan of care, the aide can perform bathing, grooming, mouth/skin care, toileting, changing bedding, feeding, light housekeeping, and companionship.



Hospice Aides cannot administer any medication, trim fingernail or toenails, or give care to other family members of the household.

**Bereavement Coordinator:** The Bereavement Counselor provides 13 months of bereavement support for both family and friends after the death of the patient. The Bereavement Coordinator offers grief counseling and education through supportive letters, telephone calls, facilitated support groups, an annual memorial service, and is a resource for referrals for counseling and other community agencies. It should be noted that following a patient death, team members from the different disciplines who worked with the patient also reach out to the family and friends. You will learn more about bereavement services in the chapter on Understanding the Bereavement Process.

**Therapy Services:** Physical, occupational, and speech therapists are available to promote quality of life and safety for the patient. The hospice nurse and physician determine if these services are necessary.

**Volunteer Coordinator/Volunteers:** The Volunteer Coordinator works with the team to decide how a volunteer can best help the patient and caregiver. Hospice Volunteers are an integral part of the team, but they do not replace the primary caregiver or substitute for the professional team. They can help the caregiver avoid “burning out” by staying with the patient while the caregiver takes time for him/herself. The volunteers’ most important roles are helping caregivers take time “to recharge their batteries” and supporting the patient. After each visit, the volunteer must document what happened and submit this information to the Volunteer Coordinator for inclusion in the patient’s chart, as well as communicating with other team members as appropriate. You will learn all aspects of volunteering in the chapter on the Role of the Hospice Volunteer.

## The Patient’s Bill of Rights

### **The patient has the right:**

1. To be fully informed in advance about the care, treatment, and any charges for services.
2. To be fully informed in advance of any changes in care or treatment to be furnished to the patient by the agency.
3. To be fully informed of all items and services furnished by the agency for which payment may be charged to the patient’s healthcare insurance.
4. To be involved in his/her care or services.
5. To make informed decisions regarding care or services including refusal of care or treatment.
6. To participate in resolving conflicts about care or service decisions.
7. To be involved in resolving ethical issues.
8. To formulate advance directives including decisions to withhold resuscitation and/or decisions to forgo or withdraw life-sustaining care.



9. To choose whether or not to participate in research, investigational or experimental studies or clinical trials.

To have complaints regarding treatment, care, or lack of respect for person or property heard, reviewed, and if possible, resolved by calling the Tufts Medicine Care at Home Triage Line at 1-800-475-8335.

10. To make complaints to the MA Department of Public Health Hotline at 1-800-462-5540.
11. To confidentiality and privacy, and to have property respected.
12. To protection of privacy of health information as required by law.
13. To have communication needs met.
14. To expect a quick response to reports of pain and symptoms.
15. To not be subjected to reprisal for exercising patient rights.
16. To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source and misappropriation of patient property:
  1. To expect that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees or contracted staff to the hospice administrator.
  2. To expect immediate investigation of all alleged violations involving anyone providing services on behalf of hospice and take immediate action to prevent further potential violations.
  3. To take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration.

## The Patient's Responsibilities

### **The patient has the responsibility to:**

1. Provide the agency with accurate information about current health status so that we can make accurate decisions concerning the type of service(s) required.



2. Provide accurate insurance and financial information and to provide timely notification of changes.
3. Give the agency complete information about the medical services that s/he is receiving, and the physician and facilities that are providing care.
4. Inform the hospice clinician about all medications or treatments that s/he is receiving.
5. Inform his/her physician, nurse, or the agency of any changes in health status, or reactions to any medications or reactions to treatments received.
6. Follow the plan of treatment as prescribed by his/her physician.
7. Notify hospice at least 24 hours in advance of any appointment that must be cancelled.
8. Work with the physician and hospice clinician to develop a pain management plan.

## **Introduction to Hospice - Homework Assignment**

Throughout this course, you will be asked to reflect on specific aspects of death, dying, and your own feelings involving these aspects of life. This homework is designed to help you become comfortable with your own story and beliefs, so that you are very aware of your own boundaries. In that way, when your patients talk with you, you can be fully present for them without going into your own story.

## **Death and Dying – A Personal Look**

This is for you. It will not be shown to anyone. Circle as many answers as are true for you. The purpose of this questionnaire is to encourage you to think about your attitudes, thoughts, and feelings about death and dying as it relates to your life. We hope that you will learn something about yourself in the process of completing this form.





1. My childhood concept of what happens after death is:
  - a. Heaven and hell.
  - b. A sleep.
  - c. Cessation of all physical and mental activity.
  - d. Mysterious and unknowable.
  - e. Reincarnation.
  - f. \_\_\_\_\_
2. Today my concept of what happens after death is:
  - a. Heaven and hell.
  - b. A sleep.
  - c. Cessation of all physical and mental activity.
  - d. Mysterious and unknowable.
  - e. Reincarnation.
  - f. \_\_\_\_\_
3. My first experience with death in my life elicited feelings of:
  - a. Fear, anger.
  - b. Sorrow, emptiness, loneliness.
  - c. Relief.
  - d. Confusion, disbelief, lack of understanding.
  - e. \_\_\_\_\_
4. The first person(s) in my life to explain to me what death meant was (were):
  - a. My parents.
  - b. A teacher.
  - c. A friend.
  - d. The television.
  - e. A person from church.
  - f. \_\_\_\_\_
5. If I could choose the circumstances of my death, I would choose to die:
  - a. Instantly of a heart attack.
  - b. At home after having lived with illness, surrounded by family, \_\_\_\_\_, and \_\_\_\_\_.
6. After my death, I would want my body to be:
  - a. Buried.
  - b. Cremated and my ashes scattered.
  - c. I don't care.
  - d. \_\_\_\_\_
7. I think about death and dying:
  - a. Never.
  - b. Once or twice a week.
  - c. Daily.
  - d. Constantly.
8. When I was young, the subject of dying was talked about in my family:
  - a. Openly.
  - b. With some sense of discomfort.
  - c. Only when necessary and then with an attempt to exclude me.



- d. As though it were a taboo subject.
  - e. I never recall any discussion of death.
9. If my physician knew that I had a terminal disease, I \_\_\_\_\_ want her/him to tell me.
- a. Would.
  - b. Would not.
10. If I learned that I had a terminal illness, I would:
- a. Not tell anyone, including my family.
  - b. Be shocked, confused, panic stricken.
  - c. Not be able to accept the fact that I was facing a life-threatening illness.
  - d. Continue on normally until symptoms began to manifest themselves.
  - e. \_\_\_\_\_
11. I would most want to talk to \_\_\_\_\_ about my dying.
- a. My spouse.
  - b. An immediate family member.
  - c. A friend.
  - d. A clergy person.
  - e. A physician/nurse.
  - f. \_\_\_\_\_
12. I probably would feel \_\_\_\_\_ about talking with someone about my dying.
- a. Embarrassed.
  - b. Distressed.
  - c. Willing.
  - d. At ease.
13. When I'm notified of a funeral, I:
- a. Usually decline gracefully.
  - b. Attend if at all possible.
  - c. Hate to go.
  - d. Dread it, but usually go.
  - e. Am happy to attend.
  - f. \_\_\_\_\_
14. The purpose of a funeral is to:
- a. Honor the person who has died.
  - b. Offer condolences to the family.
  - c. Grieve this loss with the community of family and friends of the deceased.
  - d. \_\_\_\_\_
15. When I think of my own death, my greatest fear is:
- a. Dying in pain.
  - b. Dying alone.
  - c. Leaving family and friends – everything I have known in this life.
  - d. Not having finished what I'm here for.
  - e. Not knowing what lies ahead.
  - f. \_\_\_\_\_

## Readings on Introduction to Hospice Volunteering

Lynn, Joanne, M.D. and Joan Harrold, M.D., *Handbook for Mortals: Guidance for People Facing Serious Illness*. Oxford University Press, 1999. ISBN 0-195-11662-3 A practical guide for choices, symptoms, and emotional and spiritual issues around death and dying.

Andreae, Christine. *When Evening Comes: The Education of a Hospice Volunteer*. Thomas Dunne Books. 2000. The author traces her evolution from novice to seasoned hospice volunteer through 15 stories of working with women at the end of their lives in rural Virginia. The author writes of some of the difficulties, as well as the immense rewards. All proceeds for the book benefit the Blue Ridge Hospice in Virginia.

Albom, Mitch, *Tuesdays With Morrie*. Doubleday, 1997. A former student connects with his college professor who is dying from ALS. Fourteen very moving "classes with Morrie" are recounted.

Beresford, Larry, *The Hospice Handbook: A Complete Guide*. Little Brown & Company, 1993. ISBN 0-316-09138-3 This book devotes a couple chapters to the history of the hospice movement and the make up of the hospice team. In addition it describes the differences between home-based and institutional-based hospice programs. Contains a description of Medicare coverage, which may no longer apply.

Webb, Marilyn, *The Good Death: the New American Search to Reshape the End of Life*. Bantam, 1997. A journalist's well-researched effort to describe dying in the United States, review current law, and offer recommendations for ensuring "good deaths."

Ray, M. Catherine, *I'm Here to Help: a guide for caregivers, hospice workers, and volunteers*. New York: Bantam Books, 1997 ISBN 0-553-37797-3. How can you get people to open up to you? How can you truly hear what someone is saying in non-verbal as well as verbal communication? How can you respond without giving advice or offense but still offering guidance and help? Since 1985, M. Catherine Ray's workshops and seminars have provided hospice workers with the training and techniques they need to communicate with the incurably ill and their families. Backed by interpersonal communication principles, models, and theory, this practical, clearly written handbook teaches everyone who works with terminally ill patients what to say and what not to say, how to manage conversations, and how to listen effectively in dozens of situations.

Kubler-Ross, Elisabeth, M.D., *The Wheel of Life; A Memoir of Living and Dying*. This is Dr. Kubler-Ross' final book, written during what she knew was her own final illness. It is both a book about her own remarkable life and an inspiration on how to live life fully and with joy.

### Videos/DVDs

Moyers, Bill. *On Our Own Terms: Moyers on Dying in America*. Bill Moyers' four-volume VHS on death and dying may be available from your local library, or it can be purchased as either a DVD or VHS from WGBH's web site store. The series vividly presents the issues faced by a number of different people who have a progressive disease, and how both the patients and their families try to cope with their losses.



## Module Evaluation – Introduction to Hospice

Name \_\_\_\_\_ Date \_\_\_\_\_

List some of the things you need to do in order to complete this hospice volunteer training.

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What are the basic principles of hospice philosophy and goals?

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What are some services that hospice provides for patients and their families?

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How do hospice services differ from the medical model of treatment?

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What is the volunteer's role in the hospice team?

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## The Role of the Hospice Volunteer

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### On Being a Volunteer - Excerpted from Hospice Hawaii's 1984 Annual Report

When hospices were in their formative years in the 1970s, there was a great deal of discussion about the effects of “cumulative grief,” i.e., how were volunteers, staff, et al., going to cope with witnessing multitudes of deaths over a period of time? Grim predictions of stress and burn-out permeated the literature, but the anticipated calamities never materialized. People either found a rewarding niche in hospice or they quietly went away. No one can adequately predict who is going to find hospice work rewarding: a wise person recognizes whether he or she is finding some sense of fulfillment in this field and, if not, will hopefully seek service in another area.

As hospice workers, we repeatedly hear two comments whenever anyone discovers what it is we do: 1. “You must be a wonderful person.” 2. “That must be awfully depressing.” Let’s allay both misconceptions.

First of all, we are not wonderful people. We are ordinary people who have been fortunate enough to have been placed in the extraordinary position of attempting to help others grapple with the very ordinary events of death and dying. Secondly, this work is decidedly not depressing. Often, it is



sad, and we are able at times to cry. More often than not, we can find some humor in the situation which we share with our patients and their loved ones. Our rallying point is the alleviation of pain, whether it be physical, emotional, spiritual, financial, or psychological.

As members of Hospice Hawaii, we should be grateful for the opportunity to be able to assist patients and families during this most trying of times: impending death. Each of us receives so much more than we are able to give. We become more aware of our own mortality. This leads us to heightened senses of responsibility and compassion: any one of us could be the person lying in that bed. Over and over, we witness confirmation that the most meaningful accomplishment in life is the development and nurturing of relationships, realizing more and more that they are very precious, albeit transient, commodities. Repeated confrontations with the thresholds of life and death – or, if you will, immortality – actually rub our noses in the Present. We develop the good sense to “Be Here Now.” And after all is said and done, we learn not to take things quite as seriously as once we might have. We achieve the graciousness to dance a little lighter through life, rather than wallow in it, and to be more accepting of the whimsies of Fates, rather than raging against those events we are powerless to change.

My point is simple: **Let’s not pat ourselves on the back for the good work that we do – doing good work, or excellent work, is our task. Rather, let us appreciate the good our work does for us: enhanced awareness of the ability to let go.**

## Hospice Volunteers - An Integral Part of the Hospice Team

Tufts Medicine Care at Home volunteers are individuals from diverse backgrounds whose services supplement the care provided by the patient’s family and by professional staff. According to Medicare’s *Hospice Conditions of Participation*, administrative and direct care volunteers must provide services in an amount that equals 5% of the total patient care hours for all paid hospice employees and contract staff. Last quarter, our volunteers provided 16%! In meeting/exceeding this 5% requirement, not only do we demonstrate hospice’s cost saving measures to Medicare, but we also tap into the grass roots nature of the modern hospice movement.

We find that each of our volunteers brings unique qualities and compassion to the services they provide. Our volunteers often say that while they felt compelled to make a difference in the life of someone who is dying, they ended up feeling like they had been given a gift from doing this work. Now that you have entered into this direct care training, we at Tufts Medicine Care at Home look forward to you becoming a part of our dynamic hospice team.

## Hospice Volunteer Opportunities

There are many ways that volunteers can support hospice patients and families, both directly and indirectly. After completing this training, most of our direct care volunteers begin by offering companionship visits; some expand upon the ways they volunteer within hospice, and go on to serve in different capacities, as well. Volunteering in various ways for hospice can keep the volunteer experience fresh. Here are different opportunities for you to help:



- **Companionship** – Offering regular friendly visits in the home and/or in nursing facilities, providing the patient and/or primary caregiver an opportunity to discuss their feelings, reminisce about the past, etc.
- **Respite** – Providing the caregiver an opportunity to get out of the house to take care of him/herself: to prevent caregiver burn-out, to attend celebrations, to go to the doctor, etc. This volunteer service is provided on a PRN basis (per required need).
- **Pet Therapy** – Offering pet visits to specific patients in facilities. Dogs eligible to provide this service have been previously “vetted” as therapy animals by another organization (TDI, Delta Society); the volunteer carries specialized insurance through the therapy dog organization.
- **Veterans** – Pairing up our volunteers who have served in the military with patients who are veterans, as well. The bonds that are formed between veterans are remarkable. Our veteran volunteers also participate in the **We Honor Veterans** program, delivering pins and certificates to our patients who have served in the military; these are given out on an individual as well as a group basis.
- **Vigil Team** – Being part of a volunteer team that sits in shifts with a patient who is actively dying. This may be at the request of the patient, who does not want to be alone at the time of death, or it may be requested by the family. The vigil volunteer may be alone with the patient or supporting the family/friends by companionship while their loved one is doing the work of dying. Specialized training is required to be part of this team.
- **Bereavement** – Assisting the Bereavement Coordinator to follow up with those who are grieving the loss of a loved one. Volunteers may make phone calls, pay visits, or provide support at bereavement programs. This area requires additional training.
- **Administrative** – Helping out in the office on different projects, such as the Memorial Service, the volunteer newsletter, bereavement mailings, special programs/fundraising, etc.
- **Professional Volunteers** – Providing specialized direct care to patients that requires certification/licensure from an accrediting organization to perform services (massage, reiki, therapeutic music); providing administrative expertise in the areas of computers, graphic design, copywriting, etc.

## [The Volunteer as a Member of the Hospice Team](#)

### *The Relationship between Paid and Volunteer Staff*

Hospice philosophy and services depend upon both professional and volunteer workers to fulfill organizational, patient, and family needs. It is widely recognized that volunteers provide the type of patient/family support that differentiates hospice from other types of care for the sick and dying. Volunteers provide essential support to patients and families, serving as another set of “eyes and ears” for the interdisciplinary team: by observing special needs that patients/families may have, and reporting them to the Volunteer Coordinator or a member of the team (nurse, social worker,





chaplain, or bereavement coordinator), the volunteer helps the team to work more effectively. This makes the volunteer invaluable. When in doubt whether or not the information is important, volunteers are encouraged to call in their observations.

Members of the interdisciplinary team can be resources for volunteers, as well. The primary nurse is available to answer medical questions that may arise (regarding the patient's symptoms, diagnosis, ways a volunteer can help, etc.). The social worker is there to support volunteers should issues come up about processing loss, complicated families, psychosocial dynamics, etc. And the chaplain is a resource in processing spiritual issues and questions, as well.

Volunteers are invited to attend Interdisciplinary Team meeting to share their observations, as well as stay connected via phone/voicemail. Since members of the interdisciplinary team are in the field throughout the day and night, Tufts Medicine Care at Home's prime mode of communication and case conferencing is via voicemail. Volunteers should never hesitate to call and/or leave a voicemail.

## Volunteer Rights and Responsibilities

### *The volunteer has the right to:*

- Information about the patient, primary caregiver, and family with whom you will be working.
- An orientation and ongoing training to prepare you adequately for your assignments.
- Know what is required of you prior to starting your assignments.

Respect from the patient, primary caregiver, and family members, and from Tufts Medicine Care at Home. If any family member does not treat you with respect, talk with the Social Worker or the Volunteer Coordinator or Volunteer Manager.

- Situations that are not hazardous to your well-being.
- Feedback on the effectiveness of your volunteer work to enable you to improve your abilities to help others.
- Privacy with regard to your address and phone number. See page 9 for the Phone Policy.

Guidance, direction, support, and appreciation on a regular basis from Tufts Medicine Care at Home Volunteer Services Department staff.



***The volunteer accepts the following responsibilities:***

- To work as a member of the Hospice team, accepting supervision from and communicating relevant information to the Volunteer Coordinator, the Social Worker assigned to the patient, and other team members, as needed.

To uphold through his/her actions the mission and vision of Tufts Medicine Care at Home

- To respect the confidentiality of information received through hospice work.
- To continue the process of learning and personal growth by participating in ongoing education and support programs offered to volunteers.
- To inform the Volunteer Coordinator if you are unable to serve your patient or his/her family because of an infectious disease.
- To commit an agreed amount of time per week to hospice, preferably for a minimum of one year.

***Tufts Medicine Care at Home accepts the following responsibilities:***

- To provide volunteers with orientation, training, supervision, and support.
- To treat volunteers as respected members of the hospice staff, respecting their unique gifts.
- To listen to volunteers' ideas, opinions, and assessments of the program, and to act on their recommendations.
- To provide volunteers with opportunities for growth and advancement through ongoing educational offerings and personal support.

## Policies and Procedures

***Qualifications to Volunteer:***

1. Completion of Hospice Volunteer Training
2. Not actively grieving a recent death of someone close (ie. within past year)
3. Able to listen; open to learning about others' experiences with loss and death; willing to learn from one's own experiences.
4. A non-judgmental and respectful attitude towards others
5. Open to ongoing training and supervision; attend monthly support group.



6. Able to recognize and report medical and emotional problems immediately to hospice.
7. Able to work as part of a team.
8. Be receptive to all aspects of hospice philosophy and recognize the necessity of confidentiality in hospice work.
9. Be in good health, both physically and emotionally
10. Be dependable, following through on given assignments and documentation; contacting the Volunteer Coordinator if any change in scheduling is necessary.
11. Carry automobile insurance at the minimum required by Massachusetts/New Hampshire State Law. Should a volunteer be involved in an auto accident while on hospice duty, his/her own insurance is primary, which subsequent coverage through Tufts Medicine Care at Home. All volunteers are covered for liability.
- 12.

### Providing Comfort for the Hospice Patient/Family Care:

#### Direct Care Volunteers Provide Emotional Comfort By:

- Allowing the patient/family to express their feelings and providing needed emotional support. Emotional comfort may come from talking, actively listening to music, doing a hobby/activity enjoyed in the past, a wheelchair ride, etc.
- Carrying messages, writing letters, light housekeeping, which might be difficult or impossible for the patient/family to accomplish.
- Communicating to the Volunteer Coordinator if the patient/family requires more support be professional services. The goal is to assist patient/family members in working towards a healthy adjustment to loss.
- Being present with the patient/family at the time of death, if necessary or requested.

#### Providing Physical Comfort:

- The volunteer has been fully oriented to the specific physical needs, limitations, and special medical problems of each patient assigned.
- **Volunteers DO NOT administer medication, feed, toilet, or transfer patients.** Administering medication is the responsibility of the patient, primary care person, or hospice nurse. The volunteer's role in administering medication is one of assistance only, such as helping the patient assume the proper position, setting the water glass within reach, or helping a blind patient to identify the time and location of their medication. The nurse or family member assists the patient by preparing the correct dosage in an appropriate container. If a medication need arises when the volunteer is alone with the patient, the



volunteer should contact the hospice nurse, who will come to administer the medication. If a patient is having difficulty taking medication by mouth, this should be reported so that an appropriate alternative method can be prescribed.

- At no point will the volunteer provide patient care that a nurse, doctor, or home health aide might provide.
- The administration of a back rub or supervision of ambulation are examples of physical comfort activities that volunteers can complete.
- The on-call nurse must be contacted when any questions/concerns arise regarding patient care and/or the role of the volunteer. Hospice staff is available 24 hours/day, 7 days/week.

## Supervision

An essential part of processing your experiences as a direct care hospice volunteer is through supervision with the Volunteer Services Manager. This can take the form of a phone call, an email (if it maintains patient confidentiality), or a face-to-face meeting. When questions arise, it's important to understand that your part of a team and are not alone! Only when you bring up issues and situations to supervision can we address them. Your input is always welcome. Changes in patient status should immediately be reported to the appropriate team member as well.

## Confidentiality

As addressed in the competency training for HIPAA, Tufts Medicine Care at Home adheres to a strict policy of patient confidentiality. Volunteers must be committed to the safekeeping of data or information and the restriction of data to individuals who have need, reason, and permission for access to such data and information.

Volunteers must be vigilant not to leave any patient documentation within eyesight of people who are not on the hospice team, including family and friends; this includes at home, in the car, etc. Volunteers may not refer to patients by name when not meeting with them or in the hospice office. Any breach of confidentiality is grounds for immediate termination.

## Personal and Professional Boundaries

As identified in the Communication chapter, it is in your best interest to know your limits in working with the patient and his/her family. By being direct and honest, a volunteer shows a genuine concern for other people's rights and feelings as well as their own.

- It's okay to be straightforward (assertive) with a patient and caregiver.



- It's okay to ask questions or to say that you need time to think about a request.
- It's okay to say what you are willing to do and not to do.
- It's not okay to say "Yes, I'll do it," when you want to say "No, I am unable to do it." If you are not careful and truthful about your feelings, you will become frustrated with your assignment. It will become a chore instead of a joy.
- It's okay to turn down a request. Offer to report additional needs that you can't meet to the appropriate hospice team member and/or your Volunteer Coordinator.
- It's okay to say "no" to others and even to say it again if it isn't heard the first time. It isn't necessary to offer excuses or justifications for saying "no."
- It's fine to decline a patient assignment request if it doesn't work for you.
- It is not okay to impose your own religious beliefs. Do not respond to request for visits of a religious/spiritual leader or request to read a particular prayer.

It is not okay to have an alcoholic beverage with a patient; the patient can have a drink, but you can't join him/her. You're visiting in the capacity of a hospice volunteer with Tufts Medicine Care at Home, and not as a friend.

### Phone Policy

Volunteers are asked to adhere to the phone practices that staff use: **do not release your phone number** to patients and care givers. This allows for communication to be streamlined through the agency, allowing the team to be aware of scheduling/patient issues.

- To block your phone number, dial \*67, followed by the phone number that you're calling.

### Gifts Policy

Tufts Medicine Care at Home has a strict policy whereby all staff, both paid and volunteer, may not accept money or gifts of value. Such gifts can be misinterpreted by others in the family and community. Volunteers are encouraged to suggest a donation be made to hospice if the person or family wishes to show support and appreciation. All donations should be mailed directly to Tufts Medicine Care at Home with specification that donation goes to Hospice.

### Dress Code

As a volunteer, you are a representative of Tufts Medicine Care at Home and therefore are expected to dress in an appropriate manner. A clean, neat appearance is important for safety/infection control purposes as well as our patients' perceptions of the quality of care and service they receive. All Hospice staff members are expected to conduct themselves in a professional manner, including their appearance, in order to uphold the best possible image of Tufts Medicine Care at Home in the community.



Volunteers must wear their Hospice badge (above the waist so that the ID is visible) when they are performing service. Clothing must be clean, neat, and appropriate. Nobody revealing clothing is allowed. See the Orientation handbook provided by Human Resources for a complete detailing of appropriate dress.

## Driving Policy

Volunteers are not allowed to transport patients or their family members. See section on Legal Issues.

## Legal Issues

This is a special area of law in which social policy justifies an imposition of “duty to act or perform properly” even though a volunteer is not paid. According to the law, a volunteer has entered into a special relationship with a promise to perform, and the assigning organization is relying on the volunteer’s promise.

There is liability when a volunteer does not perform a task which s/he has agreed to perform. This liability can be:

- To the person or persons whom the volunteer has agreed to perform a service.
- To the assigning organization for which the volunteer promised to perform the service; or
- To third persons who became involved due to the nonperformance of the volunteer.
- Nonfeasance, or “failure to act,” can have serious consequences. For instance, a volunteer who agrees to deliver Meals on Wheels can cause those dependent on the service to go hungry if the volunteer does not deliver the meals.
- **Do not cash checks or sign any legal papers** with or for the care recipient or primary caregiver. This is a legal issue.

A community organization can lose its credibility and reputation as a service provider and important community resource when volunteers fail to perform. In addition, relationships with other agencies and organizations can be disrupted or damaged. An organization’s fundraising ability may be reduced.

In order for volunteers to experience greater success and satisfaction in their assignments and reduce risk, they should be given basic guidelines on how to conduct themselves as agents of Tufts Medicine Care at Home.

## Getting a New Patient Assignment



Referrals for a volunteer may come from any member of the Interdisciplinary Team (IDT). The Volunteer Manager or Volunteer Coordinator will make every effort to assign a volunteer to the patient/caregiver in a timely manner, based on both the needs of the family and the availability/ skills of the volunteers.

Volunteers should feel free to ask questions, and to ask for additional support or supervision as needed. As the old adage goes, the only dumb question is the one not asked. You also should be able to recognize and communicate to your supervisor when you are in over your head. Ignorance, combined with over-enthusiasm or over-zealousness, is no excuse and can have unanticipated consequences. Tufts Medicine Care at Home has a duty to provide you with the proper training, equipment, supervision, and support required for success on your assignments. However, you also have the responsibility not to undertake tasks if you feel unprepared or are incapable of performing them. You need to know that both you and Tufts Medicine Care at Home may be at risk legally if assigned tasks are not performed properly.

1. All patients are eligible to receive volunteer services. Certain criteria may deem a patient/family high priority for an early referral:
  - a. Short prognosis
  - b. Recent diagnosis
  - c. Lack of support – no family/friends involved in care
  - d. Primary caregiver is elderly, health or psychosocial issues
  - e. Patient/family specifically request volunteer support
2. Any Tufts Medicine Care at Home staff member, including volunteers, may make a volunteer referral by contacting the Volunteer Department.
3. When a member of the IDT determines a volunteer is needed, they must communicate their request through EPIC electronic medical records system, or using the manual (paper copy) Volunteer Request Form.
4. Assignment of volunteers is based upon (but not limited to) the following patient information which should be provided by the requestor at time of the referral:
  - Type of volunteer service requested
  - Times preferred, if any
  - Preference of patient/caregiver
  - Patient Description (i.e. hearing impaired, visually impaired, etc.)
  - Veteran Status
  - Patient Hobbies/Interest
  - Geographic Location
  - Safety Measures
  - Activities Permitted
5. When assignment is made, IDT receives emails and “Volunteer” is added to Care Team Attribute, with volunteer’s name in the comment box.
6. Assignment spreadsheets are shared weekly with Clinical Team Manager and weekend nurse.

### Tips To Remember When You Are About to Walk Through the Door:

Whether you visit your assigned patient in his/her home or in a facility, here are some guidelines:



- Show up. Pay attention. Don't attach to the outcome.
- Before you visit, stop for a moment and center yourself. Be aware of your actions of body, mind, and speech. Quiet and ease are contagious; be at peace.
- Wear your identification badge at all times. Identify yourself by name to the patient and his/her family, explaining why you are there. For example: "Hello! I'm Fiona Smith, and I am here to pay you a visit. Would you like to chat for a while?"
- Read and respect isolation signs. Ask somebody if you are unsure how to proceed. Wear mask, gown, or gloves for protection when indicated.
- Read and heed posted signs: HOH (hard of hearing), blind, NPO (nothing by mouth). When in doubt, ask! Questions regarding hospital policies or procedures are appreciated.
- If the patient's door in a facility is closed, knock for permission to enter. Similarly, if the bed curtains are shut, ask for permission to enter.
- If doctors or nurses are with the patient, leave the area and return later.
- Focus your attention on the patient. Stand or sit where the patient can see you easily, but do not ever sit or lean on the bed.
- Don't perform personal care services (bathing, toileting, repositioning). There are people on the team (home health aides, nurses, therapists) who can help the patient where appropriate.
- Encourage patients to talk about how they feel emotionally rather than discussing how they look. Appearances are deceptive, and while you may think the patient looks alright, the patient may not feel that way.
- Listen! Listen much more than you talk.
- Before offering a drink or food, make sure that you know the patient's diet.
- Refer special needs to the Primary Nurse, Social Worker, or Chaplain.
- Visit only those designated patients, floors, or areas that are assigned to you.
- Be vigilant of non-verbal signs of pain (grimacing, furrowed brow, moaning, agitation, restlessness, breathing more rapid, picking at the air).

Important phone numbers that you might add to your cell phone include the following:

- *Immediately* report any suspicions of abuse (physical, emotional, sexual, or financial) to the Volunteer Coordinator.
- For medical/emergency issues, call hospice at **800-475-8335**. During office hours, you will be connected with the Triage Nurse. And the on-call hospice nurse is always available to speak with a volunteer after-hours. Hospice functions on a 24/7 basis.





## Guidelines for Emergencies

It's always good to be prepared, should an emergency situation present itself when a volunteer is on assignment. It is important for the volunteer to remain calm, call hospice, and focus on helping the person in need. **DO NOT CALL 911.** Those responders are trained to give life-saving care, and that may not be what is required in this circumstance. If the patient has signed a DNR (Do Not Resuscitate), the patient has made a legal declaration of the care s/he wants to receive and does not want to receive.

The only situation where calling 911 would be appropriate is if there is an obvious fracture or massive bleeding.

### When in the Patient's Home

**Call Hospice at 800-475-8335.** This number connects you with a Tufts Medicine Care at Home Triage Line where a nurse will be able to assist you.

### When in a Hospital or Nursing Facility

- **Ask the facility's staff for assistance.** They will understand the implications of the DNR and give appropriate assistance.

**Call Hospice at 800-475-8335.** This number connects to Tufts Medicine Care at Home Triage Line where a nurse will be able to assist you.

## VOLUNTEER DOCUMENTATION GUIDELINES

Written "Care Reports" are submitted by volunteers to document their involvement with a particular patient, to enhance continuity of care and to review volunteer performance. These reports are an important way of keeping our clinical teams informed of your interaction with patients and of any issues, concerns, problems which may arise.

When the Volunteer Department receives your reports, this is the legal acknowledgement that you are visiting your patients. It is important to maintain regular contact with the Volunteer Coordinator if the frequency of your visits varies greatly.

Volunteer Visit Reports are scanned into our system and become part of your patient's electronic medical record which is a **LEGAL DOCUMENT**. The medical record can be sent to a lawyer, Medicare, or another requestor for review.



*So, with this in mind, PLEASE do keep reports relevant, brief and objective:*

- DO** use proper English and a professional nature.
- DO** submit your care reports as soon as possible, *preferably the same day as the visit*. The absolute deadline for the current month by the 5<sup>th</sup> of the following month at the latest (for instance, care reports for January visits are due by February 5<sup>th</sup>).
- DON'T** write personal notes to the volunteer department on your patient care reports.
- DON'T** mention multiple patients' names on your reports (such as: "I went to visit my other patient Mary while John was with his nurse")
- DO** use one care report for each visit.

The observations section should be a short synopsis or a simple overall description of your visit. Please remember these are **OBSERVATIONS**....and so saying: "Joe *was* sad today" is supposition, whereas saying "**Joe appeared sad today**" OR "**Joe said he was sad today**" are observations.

- Write a brief, factual narrative about your visit
- What happened during the visit? For example: *The patient visited and talked about her career. Watched TV.*
- Describe the patient's condition: Was the patient alert? What was his/her energy level like? If this was a return visit, was the patient less responsive than before? Did you notice a change since your last visit?
- If the patient had concerns, document the concern and what you did about it.
- Leave out all unnecessary editorial comments: Example: *She said no one from her family ever visits her. This is so sad.*
- If you call to set up a visit, please include the phone time in your total visit time on your visit note.
- If a caregiver no longer needs volunteer services, please send a visit note explaining that. The assignment will be canceled, and we will find you a new patient to visit.

Care Reports Are Completed:

- For each visit.
- For any phone call where the result is not a visit, please write a visit note about the phone call itself. This ensures that the patient's chart will reflect what is happening with volunteer services. For example, a caregiver may ask you to call back in two weeks. Your note will let the team know that your visits are on hold until then.
- For funeral/wakes/memorials.

If you are asked to provide bereavement support to a family after a patient's death, you will receive a different visit report.



**\*\*NOTE:** If your patient is expressing they are in pain, or showing signs of pain (grimacing, guarding an area, crying, clutching blankets, etc.) and they are able to rate their pain from 0-10, and they say their pain is **Level 5 or greater**, please call the office immediately so we can contact the patient's hospice nurse to evaluate. If you are visiting a patient in a nursing home, please report the patient's pain/discomfort to a staff nurse, and then call the office.

### What to do When a Patient Dies

In most cases the patient gradually becomes increasingly sick and non-responsive, and the nearness of the death is obvious to the family and team members, so the death is not a surprise. However, there are times when a patient dies “suddenly” even though s/he has been on hospice for a period of time. The hospice nurse is responsible for pronouncing that the patient has died.

A member of the hospice team will notify the volunteer of the patient's death. If you happen to be present when the patient dies, follow the protocol listed above for Emergencies. Then simply be with the family in their initial moments of grief. You can simply sit with them as they try to accommodate themselves to the shock. If they ask you to do something specific, such as phone another family member to give them the news, do it if you are comfortable doing so. Otherwise you might offer to bring them the phone so they can do it themselves.

Following a patient assignment to its conclusion after the patient dies, volunteers are encouraged to make a condolence phone call to the family/caregiver. Attendance at the wake or funeral is also encouraged, as volunteers often say that it is a part of a healthy process that facilitates a sense of closure. On occasion, some direct care volunteers do an additional Bereavement Training in order to specifically continue to support the family.

Should you find that you require support in processing the loss of your patient/s, please to not hesitate to call the Volunteer Coordinator, Social Worker, or Chaplain. The team is here for you.



## Ongoing Support and Enrichment Training

In addition to quarterly enrichment trainings offered to volunteers for further skill development, Tufts Medicine Care at Home provides a monthly Volunteer Support Group for all direct care volunteers. The meetings take place at the High Pointe House in Haverhill, our Lowell and Malden locations. Weekly and monthly emails let volunteer know times, and locations of each meeting. It is an expectation that if you volunteer with Tufts Medicine Care at Home, you will have regular attendance and participation in this support group. This is an important opportunity to:

- Process issues that come up in working with hospice patients/families
- Normalize feelings related to this work
- Minimize any sense of isolation
- Offer support and ideas based on your past experience to other volunteers
- Connect with other like-minded people
- Be part of a wonderful volunteer team
- Stay healthy

**Attending these group sessions is mandatory for being a hospice volunteer with Tufts Medicine Care at Home**, as support group participation has been shown to play a role in the prevention of compassion fatigue.

## What Does it Mean?

Common Terms in talking about End-of-Life

**ADLs (Activities of Daily Living):** These are the routine life tasks that people do every day. The six basic ADLs are eating, bathing, getting dressed, toileting, transferring and continence. Inability to perform any of these tasks is a consideration for hospice eligibility.

**Advance Directive:** Also referred to as a living will, an advance directive is a legal document that allows an individual to specify what healthcare actions may be taken if the individual is no longer able to make decisions for his or herself due to illness or incapacity.

**Aspiration:** occurs when food particles or fluids are accidentally sucked into the lungs. This can occur at end of life if an individual who has trouble swallowing is asked to eat or drink fluids.

**Assisted Living Facility (ALS):** Assisted living facilities are a housing option for senior adults who may require some assistance, but do not need nursing care or other medical support provided in nursing homes.



**Atropine:** Atropine drops are used in the hospice setting to reduce excess mucus secretion and saliva production when patients are no longer able to clear their throats themselves.

**CMS (Centers for Medicare & Medicaid Services):** is a federal agency within the United States Department of Health and Human Services that administers the Medicare program and partners with state governments to administer the Medicaid program.

**CPR (Cardiopulmonary resuscitation):** is an emergency procedure performed when the heart stops beating.

**DNR/AND (do not resuscitate/allow natural death):** A DNR is a legal order to withhold CPR or other life-saving measures in accordance with the patient's wishes to allow natural death to occur if they stop breathing or their heart stops beating.

**Durable Medical Equipment (DME):** is any medical equipment that provides therapeutic benefits to a patient with a medical condition or illness. DME includes items like hospital beds, wheelchairs, walkers, oxygen, and lifts.

**Edema:** is the abnormal buildup of fluid in the body that often causes swelling in the feet, ankles, legs, arms, hands, or face.

**Comfort Kit (Emergency Symptom Kit):** The comfort kit is a small quantity of medication that can be used to rapidly treat symptoms that can occur in a patient with a terminal illness.

**Feeding Tube:** A feeding tube is a device used to supply nutrition to an individual who is having trouble swallowing or drinking. The small plastic tube is inserted through the nose, abdomen or small intestine.

**Haldol:** Sometimes referred to as Haloperidol, Haldol is used to treat delirium and terminal agitation.

**Healthcare Proxy:** Also known as a durable power of attorney (POA), a healthcare proxy is a legal document that appoints a trusted individual to make medical decisions on your behalf if you are no longer capable of making your own decisions due to illness or incapacity.

**Hospice:** is a philosophy of care that focuses on providing physical, emotional and spiritual support intended to comfort and improve the quality of life of terminally ill patients.

**Hospice Discharge:** When a patient is determined to no longer be eligible for hospice services, the patient may be discharged from hospice, and hospice services will cease.

**Informed Consent:** In order to have true informed consent, a patient must understand all the risks, benefits and alternative options associated with the care being provided.

**Interdisciplinary Group (IDG) Meeting:** The full hospice care team must meet to discuss each patient and review their plan of care every 14 days.

**Lorazepam / Ativan:** is a benzodiazepine medication used to treat anxiety in terminally ill patients and can be used alone or in combination with other medications to treat nausea and vomiting.

**Medical Power of Attorney:** is the person selected by an individual to make healthcare decisions on their behalf when they are incapacitated or no longer able to make decisions on their own.



**Medicare Benefit:** If a patient meets Medicare hospice eligibility criteria, the cost of their care will be 100% covered by Medicare.

**Methadone:** is an opioid used for pain relief. It relieves pain without providing the euphoric feelings that lead to addiction.

**Mottled Skin:** When the heart is no longer able to pump blood effectively, blood pressure slows throughout the body. It can cause red or purple marbled appearance in the extremities, which is called mottling.

**Palliative:** is treatment to manage the pain, symptoms and side effects of chronic illness. Patients may receive palliative care at any stage of their illness and can continue to pursue curative treatment.

**Patient's Bill of Rights:** The hospice patient bill of rights is a list of rights guaranteed to patients and their families.

**Recertification:** After a patient has been receiving hospice care for six months, they must be evaluated for recertification to confirm they still meet hospice eligibility requirements. After the six-month point, recertification is required every 60 days.

**Roxanol / Morphine Sulfate:** In the hospice setting, Roxanol is used to treat severe pain and shortness of breath in terminally ill patients.

**Terminal restlessness:** or terminal agitation is a common symptom at end of life that includes extreme agitation, anxiety and confusion.

**Ventilator Withdrawal:** is the process of removing life support from a patient who is no longer able to breathe on their own.

## Journal Assignment: Role of the Volunteer

Write about your inspiration to become a hospice volunteer. What strengths will you bring with you when you visit patients and their families? What areas do you think you will need more support with?

## Readings on The Role of the Volunteer

Linder, Eric, *Hospice Voices: Lessons for Living at the End of Life*. Lanham, Maryland: Rowman & Littlefield Publishers, Inc., 2013. Linder writes about his experience as a hospice volunteer.

Bennett, Mary Jo. *When Autumn Comes: Creating Compassionate Care of the Dying*. Universe Books. 2006. Based on her years of experience as a hospice volunteer, the author offers practical advice and thoughtful reflection on the art of caring for people who are terminally ill.

Goldberg, Stan. *Lessons for the Living: Stories of Forgiveness, Gratitude and Courage at the End of Life*: Trumpeter Books. 2009. Part memoir and part practical guide, the book provides a compassionate look at being present with those who are dying. This book shares insightful awareness of the end of life and presents opportunities for emotional and spiritual growth for all of us on life's journey.

Joseph, Melissa. *Moments with Baxter*. San Diego, CA: Sage Press, 2009. Fabulous book about the work a therapy dog has done with hospice patients, families, and staff.

Resnik, David B. *Dying Declarations: Notes From a Hospice Volunteer*. Haworth Pastoral Press, 2005. A candid account of a volunteer's initial concern that hospice would be a depressing undertaking. Instead, the author relates touching stories that illustrate the uplifting and enriching nature of working with people who, at the end of life, are willing to strip away all that is unimportant and embrace their true priorities.



## Module Evaluation – The Role of the Volunteer

Name \_\_\_\_\_ Date \_\_\_\_\_

In what ways can you provide support to a hospice patient and his/her family?

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How often do you need to submit documentation to the Volunteer Coordinator?

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What would you do if the patient asked you to bring her medication to her?

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What would you do if there was an emergency when you were visiting a patient?

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Why is it important to attend the monthly Support Group?

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Name two ways that a volunteer could incur legal problems in working with patients:

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Please note what you found most interesting during this module.

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Please describe any challenges or difficult issues that arose during this module.

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Do you have any suggestions for changes to the course material presented?







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# Infection Control & Care and Comfort

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## The Infection Control

Infection control is composed of many facets of patient care, chief among which are the following

- Hygiene policy
  - Hand hygiene: sanitizing gel before and after each visit, followed by washing hands. Rubbing gets the germs off.
  - Standard Precautions
  - Hepatitis B, Tuberculosis, Flu, MRSA, C-Difficile
  - Blood borne pathogens and personal protective equipment (for Hepatitis B, HIV)
- Distribution of gloves and hand sanitizer.

## Care and Comfort Measures

- I. Discussion of what hospice care is:
  - A. Who can receive hospice
    - i. Doctor's order required
    - ii. Payer sources (Medicare and private)
    - iii. Admission criteria - local coverage determination for Alzheimer's included in Fact Sheet section
  - B. Nursing role: managing pain and fear
    - i. Providing access to support 24/7 through the primary nurse and on-call nurse - educating patient/family on giving medicine and non-medical approaches to help with symptom management
    - ii. Comfort Kit placed in the home for when it is needed – (liquid morphine for pain, Ativan for anxiety, nausea and sleep, Haldol for terminal agitation and vomiting, Atropine for congestion, etc.)
  - C. Recertification process – IDT approves the plan of care as long as hospice care continues to be warranted
  - D. Live discharge from hospice care when there's improvement (such as weight gain, improvement in eating, sleeping and mobility)
  - E. Pronouncement of death
    - i. Family can wait to call hospice, so that they can have time with their loved one's body in order to say goodbye
    - ii. Hospice nurse has a doctor's order enabling him/her to pronounce the deceased (in facilities, pronouncement provided by RN on staff)
    - iii. Post mortem care – washing and dressing the body for transfer
    - iv. Nurse educated family on destroying narcotics
    - v. Family or nurse calls the funeral home to take the body

- II. Ethical considerations:
  - A. Hospice is about living, and making (however many days are left) the patient as comfortable as possible. It is a misnomer that hospice is for the last days of life.
  - B. Discussion of the legal and ethical aspects of suicide, euthanasia, and palliative sedation. We don't hasten death or prolong suffering.
  - C. Compromised Human Dignity.
  - D. Massachusetts Health Care Proxy: a physician or nurse practitioner must deem the patient incompetent in order to invoke the HCP
  - E. Advanced Directives/DNR (Do Not Resuscitate – also known as the comfort care form)/MOLST/Full Code
  - F. Patient's right to revoke hospice at will.
  
- III. Understand that the diagnosis does not define who the patient is:
  - A. The role of palliative care - pain control and symptom management
  - B. Symptoms you may expect with common primary and secondary diagnoses.
    - a. Lung disease (Chronic obstructive pulmonary disease)
    - b. Protein calorie deficiency
    - c. Cancers
    - d. Cardiac (congestive heart failure, cardiac myopathy, aortic stenosis)
    - e. Dementia (Alzheimer's, vascular, Lewey body) – to be addressed in Dementia Care training
    - f. Diabetes Mellitus
    - g. Renal failure
    - h. Liver disease
    - i. Neurological disease (CVA, ALS, MS, MD, Parkinson's)
    - j. Acquired immune deficiency syndrome (AIDS)
  - C. Treatments and their side effects.
  - D. Non-verbal signs of pain and/or discomfort (see fact sheet)
  - E. Caregiver issues and concerns.
  - F. Food/eating/feeding.
  
- IV. The volunteer's role in care and comfort.
  - A. Volunteers help nursing by listening to the patients and their families, and reporting back to the hospice team. By doing this, you help the team in making sure that the patient's symptoms are managed and that his/her needs are being met.
  - B. Volunteers DO NOT give any meds...ever!**
  - C. Hospice's policies for hands-on care by volunteers.
  - D. Non-skilled care and comfort measures that volunteers can do. You can adjust blankets, put a cool cloth on the forehead, adjust a fan, and open/close a window. Reading aloud, writing, prayer, singing, holding hands, and anything that brings the patient pleasure can also bring comfort.

- E. **You can't transfer, toilet, feed, etc.**
  - F. Signs of approaching death – please see the pamphlet *Gone from my Sight* in the front pocket of this manual.
- V. The role of the Home Health Aide:
- A. Specialized training required in hospice care
  - B. Provides care in bathing, dressing, toileting, feeding, and transferring
  - C. Can offer companionship initially, developing a relationship with patient prior to when patient actually requires care
  - D. Cannot give meds or run errands

## Tips for Dispelling Myths of Opioids

Opioids, often called narcotics, are commonly used in hospice and palliative care to keep patients comfortable. Many patients, family members and even healthcare providers are afraid to give these medications because of what they have heard in the news, on television and from friends. The following information is designed to help dispel some of the myths surrounding the use of opioids.

**Myth:** Opioids are addicting.

**Reality:** There is a difference between physical dependence and addiction. Physical dependence is a state in which physical withdrawal symptoms occur when a medication is stopped or decreased abruptly. This is expected. Addiction is a chronic disease in which people have a poor control over drug use and continue to use the drug despite physical and social harm. Addiction is rare for patients who are terminally ill when the goal of care is comfort.

**Myth:** Opioids cause respiratory depression.

**Reality:** When opioids are adjusted slowly to provide pain relief, respiratory depression is rare.

**Myth:** If a person takes large doses of opioids early in their disease process, the opioids will not be as effective later on when he/she needs higher doses.

**Reality:** There is no maximum dosage for opioids. A patient should get whatever dose is needed to provide pain relief. One should not focus on “the numbers” but instead be focused on making sure the patient’s pain is controlled.

**Myth:** Giving opioids to a terminally ill patient will hasten death.

**Reality:** Research shows that the use of opioids does not lead to a quicker death. Withholding pain medication at the end of life is not appropriate when medications are available to relieve pain and suffering.

**Myth:** Opioids cause a person to feel foggy and lose control.

**Reality:** When opioids are taken on a regular basis, tolerance quickly develops and the feeling of being foggy or out of control should go away within a week.

**Myth:** Opioids damage the body.



**Reality:** Opioids are very safe drugs when used as directed. Of interest, the American Geriatric Society has determined that opioids are safer for older people than non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®) or naproxen (Aleve®).

**Myth:** Using opioids means that you are a weak or bad person.

**Reality:** Because there have been many stories in the news about people who abused opioids, their legitimate use for pain has been questioned. As a result, too many people suffer with pain who could be relieved with opioids.

**Myth:** All types of pain respond well to opioids.

**Reality:** Pain caused by bone or nerve injury (neuropathic) may need the help of additional medications along with opioids to provide better relief for these types of pain.

**Myth:** You cannot give opioids to a child.

**Reality:** Children of all ages can receive opioids at doses appropriate for their weight and age and with adjustments based on physical condition. If other questions arise, please ask the nurse assigned to your patient.

Other HPNA TIPs Sheets are available at [www.hpna.org](http://www.hpna.org).

References:

Ferrell B, Coyle N. Textbook of Palliative Nursing. New York, NY: Oxford University Press; 2006.

McCaffery M, Pasero C. Pain: Clinical Manual. 2nd ed. New York, NY. Mosby Press. 1999.

Approved by the HPNA Education Committee October 2007.

Reviewed January 2009.

## Homework Assignment: Care and Comfort

Please watch the companion documentary to Atul Gawande's article, "Letting Go":

[www.pbs.org/wgbh/frontline/film/being-mortal](http://www.pbs.org/wgbh/frontline/film/being-mortal)

## Journal Assignment: Care and Comfort

Please write your personal feelings about the use of morphine and other medications for pain control. What would you want for care and comfort if you were on hospice?

## Module Evaluation – Care and Comfort Evaluation

Name \_\_\_\_\_ Date \_\_\_\_\_



What are some of the more common diagnoses that our patients may have?

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How does hospice provide comfort care?

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List some circumstances in which you might call the on call nurse vs. the patient's nurse.

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What are some ways that you can prevent infection?

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What does it mean when someone has Advance Directives in place?

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Please note what you found most interesting during this module.

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Please describe any challenges or difficult issues that arose for you during this module.

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Do you have any suggestions for changes to the course material presented?

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## SOCIAL WORK IN HOSPICE

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Medical social work began to be referred to as a specialty between 1905 and 1912 and is said to have been founded at Johns Hopkins Hospital in Baltimore, Maryland. Social work has always been an important component of the modern hospice movement. In fact, Dame Cicely Saunders, founder of the first hospice in London in 1967, was a nurse, physician and a social worker. In establishing St. Christopher's Hospice, Saunders emphasized the multidisciplinary approach to caring for the dying, the regular use of opioids to control physical pain, and careful attention to social, spiritual and psychological suffering in patients and families. In 1986, Congress



established the Medicare Hospice Benefit, which included reimbursement for social work services as a key component of the hospice interdisciplinary group. Hospice social work focuses on helping patients and their families deal with the changes and losses that accompany the end stage of a terminal illness. The goals are to ease suffering, prepare the patient for death, support the patient to die with dignity, and help the family in bereavement.

## The Role of the Social Worker in Hospice

The hospice social worker is a qualified medical social worker with specialized skills in end-of-life care. The role of the social worker in hospice includes:

- Assisting patients to adjust to their terminal illness
- Strengthening coping skills in crisis situations
- Supporting patients and families with anticipatory grief
- Strengthening family and support networks
- Assisting patients with financial and resource concerns
- Helping family and loved ones to bridge gaps, obstacles and conflict, allowing them to come together whenever possible.
- Addressing inadequate living arrangements and safety concerns
- Evaluating the need for possible placement, alternate housing, or changes in the hospice level of care
- Helping patients and families to address substance abuse or chemical dependency.
- Assisting with multidimensional symptom management
- Supporting the patient's physical, psychological, and spiritual manifestations of pain
- Helping patients and family members with behavior management associated with dementia.
- Assisting patients to address legal issues
- Supporting patients with ethnic, cultural, age-related, religious, and economic diversity
- Addressing patient noncompliance with the treatment plan
- Educating patients on the importance, use and revision of advance directives
- Assisting with funeral planning
- Supporting family members with arrangements after death
- Providing bereavement support
- Supporting the interdisciplinary team and practice

## Federal Social Work Qualifications for Hospice Care

According to the Medicare Hospice Conditions of Participation, qualifications for a hospice social worker include having:

- A Master of Social Work (MSW) degree from a school of social work accredited by the Council on Social Work Education; or
- A baccalaureate degree in social work (BSW) from an institution accredited by the Council on Social Work Education; or a baccalaureate degree in psychology, sociology, or other field related to social work and is supervised by an MSW (as described above); and



- At least one year of experience in a healthcare setting

The MSW supervisor role is that of an active advisor, consulting with the BSW on assessing the needs of patients and families, developing and updating the social work portion of the plan of care, and delivering care to patients and families. This supervision may occur in person, over the telephone, through electronic communication, or through a combination of approaches. The condition for a master-prepared social worker to supervise a baccalaureate-prepared social worker became part of the hospice Conditions of Participation in December, 2008. BSWs employed by the hospice prior to that time are not required to be supervised by an MSW.

## Medicare Coverage of Social Work Services

In hospice, social workers are core members of the hospice interdisciplinary group that work under the direction of the physician. Under the Medicare Hospice Benefit, the Centers for Medicare and Medicaid Services (CMS) reimburses for hospice social work to provide the following services:

- Assessment of social and emotional factors related to the patient's illness, need for care, response to treatment and adjustment to care
- Assessment of the relationship between the patient's medical requirements and home situation, financial resources and availability of community resources
- Assistance in obtaining available community resources to support identified needs that impact the patient's response to care
- Counseling services for the patient and family to address needs such as depression, grief, and bereavement.
- Medical social services furnished to the patient's family member or caregiver on a short-term basis when the hospice can demonstrate that a brief intervention (e.g., two or three visits) is necessary to remove a **clear and direct** impediment to the effective palliation and management of the patient's terminal illness and related conditions. To be considered "clear and direct," the behavior or actions of the family member or caregiver must plainly interfere with the patient's response to hospice services and medical treatment. Medical social services to address general problems that do not clearly and directly impede treatment, as well as long-term social services furnished to family members, would not be covered. (CMS Manual System, Pub 100-02, Medicare Benefit Policy, Chapter 9, Section 40.1.2)

## Psychosocial Assessment

The hospice interdisciplinary group is responsible for completing a comprehensive assessment that identifies the patient's physical, psychosocial, emotional, and spiritual needs related to the terminal illness. This assessment must be completed no later than 5 calendar days after the election of hospice care. In most situations, the social worker completes the psychosocial component of the comprehensive assessment to determine the needs of the patient and family. The psychosocial assessment includes the following components:



- Terminal diagnosis and any associated conditions, such as pain, depression, anxiety, and confusion
- Past experience with illness, disability, death and loss
- Social supports, including support systems and the presence and availability of informal and formal caregivers
- Role within the family structure
- Communication and decision-making style, including language preferences and the possible need for translation services
- Stage in the patient's life cycle and relevant developmental issues
- Impact of the disease on the patient's sexuality
- Spirituality, rituals and faith practices
- End-of-life decisions and desires
- Psychosocial needs
- Cultural values and beliefs
- Goals and desires related to end-of-life treatment and palliation
- Available resources and those that are needed but not available
- Coping style and crisis management skills

Once this assessment is completed, the findings are used by the interdisciplinary group to develop a plan of care so that needs may be addressed by appropriate team members. The assessment must be reviewed and updated by the interdisciplinary group no less frequently than every 15 days.

## Family Assessment

In hospice, the patient and family are viewed as a “unit of care.” This may include the patient's blood relatives or persons who are not related but have special meaning to the patient. The importance of family becomes magnified in persons with terminal illnesses. Families are often a source of support, providing transportation, care assistance, help with finances, and emotional support. However, in many situations, they may also be a source of distress, by their absence, conflicting relationships, and through projection of their own despair. The importance of family is an important concern whether the family is traditional or nontraditional, intact or disjointed, present or absent. The hospice social worker's role in assessing and supporting the family is critical to achieving positive end-of-life outcomes. The skills of social workers in family systems theory and relationship and trust building are central to creating an environment that fosters stable, if not positive, family dynamics. This begins with a thorough psychosocial assessment of the family structure, characteristics and dynamics. Problems that are identified are then addressed within the patient's hospice plan of care. Support of the family continues after death through the hospice's bereavement program.

The family assessment should include a review of:

- Structural details, such as members of the “immediate family” having a biological or legal relationship to the patient, and those who may not be related by blood but who still have an impactful relationship to the patient.

- How the patient perceives the family and associated relationships, including key members and those with authority
- Relationships that are supportive and those that are stressful.
- The family's ability and willingness to provide caregiving support to the patient.
- The presence of discord or conflicts between the family unit
- Belief systems and any conflicts that may exist with the beliefs of the family and those of the patient.
- Communication and problem-solving skills
- Associated strains, such as financial difficulties, cultural issues, and other health-related issues
- Changes in family roles and responsibilities because of the patient's illness and impending death
- Developmental stages and needs of family members, particularly if children and adolescents are involved.
- Past experiences of family members related to crisis, severe illness and death
- The geographic distribution of family members, including persons who are available to provide direct care and support.
- The desires of the patient related to communicating health-related updates to family members.
- Potentially harmful relationships, including the presence of emotional, physical, sexual and substance abuse.
- Bereavement needs of survivors.

## Hospice Plan of Care

Findings from the comprehensive assessment are used by the interdisciplinary group to develop a patient-directed, individualized plan of care to meet identified needs. These should incorporate psychosocial needs identified by the social worker during the psychosocial assessment. The plan of care should include the following components:

- The patient's terminal diagnosis supporting hospice services
- Patient and family problems and needs
- Realistic, measurable and achievable goals
- Ordered services and frequency of visits
- Interventions to manage pain and symptoms
- The level of care to be provided
- Ordered medical equipment and supplies
- Medications ordered to treat the terminal diagnosis and those ordered to treat other conditions
- Evidence of patient and family understanding, agreement and involvement in the plan of care
- Details of advance directives
- A plan for bereavement services, which includes the persons who will be involved in bereavement services; an assessment of risk factors; and the scope, type and frequency of follow-up services



Once the plan of care is developed, it must be reviewed and revised by the interdisciplinary group at a minimum of every 15 days. It must also be incorporated into other plans of care when the patient is receiving care in a nursing or inpatient facility.

## Common Social Work Interventions in Hospice

Interventions commonly provided by social workers to patients at the end-of-life include:

- Providing counseling services, including individual counseling, psychotherapy, family counseling, crisis counseling, and resource counseling
- Educating patients and families on advance directives
- Facilitating support and bereavement groups
- Providing symptom management, with a focus on addressing spiritual and emotional pain
- Participating in case management and discharge planning
- Assisting patients and families with decision-making and the implications of various treatment alternatives

## Social Work Counseling Services

Individual and family counseling is an important intervention provided by hospice social workers. Counseling is often effective in helping patients and families deal with issues such as anxiety, sleep disturbances, panic attacks, pain, nausea, depression and family conflicts. It can be used to provide support, education, and problem-solving or coping skills. Counseling may be used in combination with other interventions, such as relaxation, guided imagery, progressive muscle relaxation, clinical hypnosis, and music therapy. A family meeting is a special form of counseling used to address issues identified from the family assessment. It can be a valuable clinical tool to communicate medical information, discuss goals of care, provide care-related education, and facilitate decision-making. The social worker is often an ideal facilitator for these meetings, ensuring that the family's need for information and support are met, while encouraging a safe setting for participants to ask questions and process emotions. If the counseling needs of the patient or family are beyond the scope of the social worker's expertise, it may be necessary to refer the patient and family to a therapist or support group.

## Assisting Patients with Advance Directives

The Patient Self-Determination Act of 1990 requires that health care organizations ask patients about advance directives, recognize the patient's written healthcare wishes, and provide education about end-of-life decision-making. Common forms of advance directives include a living will, a durable power of attorney for health care, and a Do Not Resuscitate (DNR) order. A living will is a document that informs doctors and family members about medical care preferences should a person have a terminal condition and be unable to communicate his or her wishes. A durable power of attorney for health care is a document that gives another person power to make medical treatment and related personal care decisions if the person is unable to make those decisions. A DNR order is a physician's order that supports a patient's desire not to receive cardiopulmonary resuscitation in the event of death. Patients are not required to have a DNR order or an advance directive to be admitted to hospice. However, upon admission to

hospice, all patients must be given information regarding advance directives. Advance directives are governed by the laws of each state. States may place specific requirements on the use of advance directives and DNR orders, including terminology for components of advance directives and specific forms that must be used. In many states, the living will and durable power of attorney are combined into one form as a mechanism to reduce confusion and make it easier for people to make their wishes known. Hospice social workers often play a key role in introducing, discussing, and helping patients complete advance directives. They also assist patients and families in identifying options and articulating their preferences during the early stages of hospice care. To provide the best support, the hospice social worker should have a good understanding of applicable state laws that regulate advance directives. Although the social worker may assist a patient in completing the advance directive, in most situations, individuals involved in the patient's care may not witness signature of the form.

## Support Groups

The role of the hospice social worker may involve facilitating support groups within the agency or community. A support group is a group of people who gather voluntarily to meet certain needs they share in common. The goal is to provide support, information, guidance, and empowerment about a disease, condition, or situation. They also offer a supportive environment for participants to work through feelings and concerns, while learning problem-solving techniques and coping skills. Groups may have a specific focus such as loss or caregiving, or be disease-specific. They may also offer an opportunity for the social worker to provide community resources, education and insight on the benefits of hospice services. Support groups may be especially helpful as an adjunct to the agency's bereavement initiatives. In order to facilitate effective support groups, it is important for the social worker to possess the following knowledge, skills and characteristics:

- Knowledge of the topic
- Understanding of group dynamics and processes, as well as the ability to set boundaries with participants
- An accepting and nonjudgmental attitude
- Effective listening and communication skills
- An ability to demonstrate compassion, empathy, respect, and authenticity
- Flexibility in adjusting plans to accommodate evolving needs

## Bereavement Counseling

Bereavement is the period of loss resulting from death, with grief being the primary emotional response. Grief is a multidimensional process with symptoms that affect people physically, emotionally, cognitively, socially and spiritually. It is often one of the most distressing times in a person's life. The social worker and other members of the interdisciplinary team need the ability to differentiate between normal anticipatory or actual grief and symptoms that may have progressed to another clinical disorder. In most situations, grieving people respond to support and do not require formal therapy or medications to get through normal grief unless they develop a prolonged grief response. Depression is not an inevitable aspect of grief, although it is a clinical condition that may result from prolonged grief. Depression requires therapy from a skilled social worker or other practitioner, and in some cases medications may be indicated. The Medicare Hospice Benefit requires that the hospice have an organized bereavement program



with services furnished under the supervision of a qualified professional with experience or education in grief or loss counseling. Medicare does not specify the educational background of bereavement counselors, although many hospice organizations employ social workers for this role. Bereavement counseling may be offered in the family member's home, in the hospice agency, or by telephone. Bereavement counseling also extends to residents of a nursing facility when appropriate and identified in the bereavement plan of care. A grief and bereavement assessment should be completed during the first social work visit and should be included in the comprehensive assessment. This assessment should be reviewed and updated as needed but at least every 15 days. Bereavement services must be made available to the family for up to one year following the death of the patient based on a bereavement plan of care. Bereavement interventions for uncomplicated grief should focus on psychosocial support and education. Social workers need to be knowledgeable about the many ways that people grieve, without making the assumption that a survivor must talk about his or her feelings. They should proceed with caution and take their cues from the mourners.

## Life Review and Reminiscence Therapy

A *life review* is an intervention that can be facilitated by the hospice social worker to help a patient deal with his or her terminal condition and impending loss. It can help bring closure to the patient's life and demonstrate the value and significance the patient's life had on others. The life review may include an oral or written history of important milestones in the family, values or beliefs that the patient would like to pass on, instructions for survivors, and genealogical information. Making audiotapes and videotapes can be an important adjunct to the oral or written history. The process of performing a life review often helps the patient to gain perspective on life and find meaning. It also helps identify any unfinished business the patient may want to attend to before death.

## Managing a Patient's Total Pain

One of the primary responsibilities of the hospice interdisciplinary team is to manage the patient's pain at the end-of-life. In managing pain, it is important to recognize that the intense suffering by dying patients and their families involves "total pain," which includes physical, social, psychological, and spiritual pain. The presence of pain may be impacted by:

- Loss of meaning and hope
- Loss of identity due to lost roles, lost activity, and lost independence
- Anger at God and a sense of betrayal or abandonment by God
- Disruption in one's faith system
- Fear of God and punishment
- Need for reconciliation and forgiveness

Social workers need to be alert for traditional and nontraditional signs of pain, including:

- Physical symptoms of pain
- Insomnia
- Withdrawal or isolation from others
- Anxiety, fear and mistrust

- Anger
- Depression
- Guilt and low self-worth
- Hopelessness
- Despair

If these symptoms are identified, the social worker should work with the entire interdisciplinary team to make pain management a priority.

## Resource Planning and Assistance

A critical role of the hospice social worker is identifying any personal, financial, or legal needs and connecting the patient and family to appropriate community resources. This may include assistance or referrals to obtain:

- Adequate food and meal preparation
- Medications
- Safe and appropriate housing and repairs, including alternative placement if necessary
- Utilities
- Respite care
- Housekeeping services
- Waste management and pest control
- Personal care services
- Healthcare services and insurance
- Transportation
- Support group referrals
- Advance directives
- A Will and Testament
- Funeral arrangements

## Social Work Documentation

Social workers are required to provide care based on the patient's integrated plan of care. Assessment findings and interventions should be documented within each visit note. Each visit note should focus on at least one problem identified on the plan of care and reflect professional interventions to achieve the desired goal. Every two weeks (at least every 15 days), the interdisciplinary group should summarize and document the effectiveness of interventions provided and update the plan of care, including ordered visit frequencies and services. Social work documentation should:

- Be signed with the social worker's full name, credentials and date; and be legible and timely
- Allow the reader to easily identify the patient's status and condition



- Reflect the presence of a progressing terminal illness (including support of local coverage determinations)
- Support the need for professional social work services
- Include both objective and subjective (in quotations) details
- Support the patient's level of care
- Demonstrate communication, collaboration and education

## **Hospice Social Services in Nursing Facilities**

As a core team member, the hospice social worker is responsible for providing social support to patients receiving hospice services in nursing facilities. This care should be a collaborative approach with the nursing facility staff and must be specified within an integrated and coordinated plan of care. As with other hospice core services, social services must be provided to patients in nursing facilities on an on-call system, 24-hours a day, 7 days a week. Social services should be made available not only to the patient and family but also to facility staff.

## **Ethical Decision-Making**

Hospice social workers are often required to support patients facing ethical dilemmas, which are common in patients at the end-of-life. An ethical dilemma is a situation in which a person is required to make a decision based on an impactful situation. A “right” or “wrong” choice is often not evident. In supporting patients facing an ethical dilemma, the social worker helps the patient and family to evaluate alternative actions and determine:

- Which option will produce the most good and do the least harm?
- Which option best respects the rights of all who have a stake?
- Which option treats people equally or proportionately?
- Which option best serves those involved as a whole?
- Which option leads the patient to act as the sort of person he or she wants to be?

## **Supporting the Patient and Family at the End-of-Life**

Hospice social workers need the ability to recognize signs and symptoms of the patient's impending death and be able to prepare and support family members through the process. This includes helping patients, family members and caregivers with anticipatory grief, bereavement, and follow-up services.

Emotional and spiritual signs of impending death may include:

- Withdrawal
- Vision-like experiences
- Decreased socialization
- Restlessness and confusion
- Needing permission from loved ones to go



- Saying good-bye

Physical signs of impending death may include:

- Increased amount of time sleeping
- Coolness of the extremities
- Skin color changes
- Bowel and bladder incontinence
- Decreased urinary output
- Decreased appetite and thirst
- Breathing pattern changes
- Congestion and gurgling sounds with respirations

## Supporting the Whole Person

Hospice social workers, along with other members of the interdisciplinary group, support the **whole** person, including the body, mind, spirit and practical needs. In treating the **body**, the social worker helps to manage physical symptoms, such as pain, nausea, poor appetite and weakness. In order to care for the patient's extensive symptom burden, social workers need to have a good understanding of common life-limiting illnesses, their associated symptoms, and best practices for controlling them. Caring for the **mind** involves addressing the patient's emotional, psychosocial, and relationship needs. Supporting the whole person also means that the patient, family and caregivers are included; not just the disease. The **spirit** is also a component of the whole person. Although religion and spirituality have different meanings for most people, social workers, spiritual counselors, and other members of the interdisciplinary group assist patients to identify and use internal spiritual resources as a means of finding serenity and acceptance at the end-of-life. And finally, social workers play a key role in helping patients with **practical needs**. This may involve managing financial matters, preparing advance directives, finalizing a will, and making funeral arrangements. Assisting to resolve unmet practical needs helps to allow for a peaceful death. During one of the most stressful and frightening times in a person's life, the hospice social worker can enhance quality of life, supporting patients to live their final days peacefully, comfortably and with dignity.

## When Families Disagree:

### Causes of conflict:

- Most families are spread out across the country; when they return to help the patient, they come in with big ideas and are disconnected to the reality of the situation.
- Children are from previous marriages/new relationships.
- Family would rather not discuss death until they absolutely have to.
- Family members' beliefs, interests, lifestyles, experiences, etc. may all be completely different.
- Each family member reacts to stress in a different way.



- Family members may fall back on their own lifelong coping mechanisms for dealing with the situation.
- Emotional expression depends on the temperament of the individual, their family heritage, gender, etc.

### **Universal issues:**

- Family members may find themselves stressed out over any issue associated with the care of their loved one.
- Family members may argue over where the patient should die.
- Families may disagree on how to care for the surviving caregiver/spouse.
- Families may disagree on the settlement of the estate.
- Families may not be able to decide who will pay bills, feed the pets, go grocery shopping, etc.

### **Advanced Directives:**

- Every adult has the legal right to choose or refuse medical treatment.
- If an adult is no longer about to make those decisions due to mental or physical conditions such as Alzheimer's disease, they are considered incapacitated.
- Advanced directives authorize the physician to provide, withhold, or withdraw life-prolonging procedures.
- Conflicts still arise with or without advance directives.
- Sometimes the family members counter the wishes of their dying loved one and disagree with the medical/treatment team.

## **How Volunteers Can Help Patients and Families**

### **What volunteers can and can't do:**

- Encourage family members to include their loved one in their conversations.
- Some families may have problems of all kinds. There may be some problems that we can't solve.
- Encourage family members to openly communicate with others in the family.
- Validate that this is a hard time for the family.
- Notify the Social Worker or Volunteer Coordinator if the family is need of support resources.
- Remind family that Hospice has a Chaplain that is available to provide spiritual support if needed.
- Encourage the family in its efforts to become educated and informed about the illness on any subject that they need to better understand.



- Reassure them that the hospice team is doing everything we can to make the patient comfortable.
- Provide empathetic responses such as, “This must be a very difficult time for you.”
- Understand that we, as members of the hospice team, are not miracle workers.

### **Remain non-judgmental:**

- Provide unconditional acceptance to each family member (for example, you can indicate that you are listening by nodding and continued eye contact).
- Accept the family wherever they are in this process. Recognize that each family member handles crises in their own ways. Sometimes these ways are not our ways.
- A lot of the tension in the family at this point comes from the fact that individual family members (including the patient) are at different stages (denial, anger, bargaining, depression, or acceptance). Use your active listening skills so each one can feel supported no matter what stage they are in.
- Remember that the family may have had issues before the terminal illness. There may have been a chemical dependency, financial problems, family members who were not on speaking terms, and so forth. It may be that some of these issues are resolved before the patient dies, but that is not always the case.
- Be respectful of culture and religion of all family members involved.
- Housekeeping standards and cleanliness may not be how we keep our house.
- Respect the family’s wishes to use euphemisms such as calling incurable lung cancer “my problem.” This is their way of keeping the situation at a more manageable distance.

### **Don’t Take Sides:**

- It may seem that the patient is misunderstood or a family member is being taken advantage of by another.
- Encourage communication and understanding among family members.
- Be careful not to get into “triangle” traps. You do not want to mediate between parents and children, or the patient and the primary caregiver. You will only be the loser in this situation, and nobody will really win.
- Don’t make yourself out to be more loveable and caring than their family.
- Some families are loosely organized – each member does his/her own thing. Others are closely knit and more independent.
- The major comfort the hospice volunteer provides for a family is the consistency s/he offers in this time of upheaval. Take care to support family rules, roles, and systems. And if you cannot figure out what they are, ask. “That’s a big problem that you have to deal with. How have you dealt with big problems in the past?”

### **Pay Attention to Feelings:**

- Family members may be afraid to hope/plan for the future. They may struggle with the idea of losing the patient AND the “family life” they have created.
- Families ride an emotional rollercoaster – hope...despair...glimmer of hope for recovery and “life as usual”.
- Be prepared to listen to and accept a variety of emotional responses.
- Allow for tears. Don’t hand someone a tissue automatically. It shuts down emotions.
- Be attentive to everyone in the home – even the quiet family member as well as the talkative one.



- When you initiate difficult topics, ask permission to talk about the topic and give the person an “out” at your expense, rather than his/hers. For instance, say: “Can I ask a personal question, or am I being too nosy?” rather than saying “Is it okay to talk about this, or is it just too painful for you?”

### **Anger:**

- Anger is often displayed by family members. Anger towards the disease and impending death is often expressed as anger against doctors, hospitals, neighbors, family members, and hospice staff.
- By understanding that they are upset/angry with the disease, you can listen quietly to their rants and bitter comments. It’s ok to say, “It seems that you’re angry right now”.
- Letting a family member vent allows them to harmlessly get rid of negative feelings and relieves some built up tension that they have not been able to express.

### **Basic End-of-Life (EOL) Tasks for Some Patients and Families**

Patients may also need to say the following to various family members:

- I love you.
- Thank you.
- Forgive me.
- I forgive you.
- I love you enough to let you go when you are ready.

And with families who are fractious, they may need to provide assurance:

- We’re going to do our best to stay together.
- We’re here for \_\_\_\_\_ (the person that the dying patient paid special attention to).

### **Ways Volunteers Can Relieve Stressors:**

- Offer to keep the patient company while the family goes to church, out to dinner, a movie, etc.
- Reassure them not to feel guilty.
- Frustrations, resentments, and anxiousness will be less when they have an opportunity to “Change the scenery” by enjoying a pleasurable activity.
- You may want to teach some of your favorite stress management techniques to individual family members, if you feel that would be well received. “When I feel that way, it helps if I take a deep breath and close my eyes. Would you like to do that together for a few moments?”

Remember...volunteer visits are essential in helping to prevent caregiver burnout. Volunteer presence allows family members and care givers to briefly step away for a bit of respite and come back feeling refreshed.

Social Workers welcome input from Volunteers:

- To share experience

- To process issues that arise from visits
- To consider ways of coping with complicated family dynamics
- To talk through your own personal struggles as you serve these families

Advice to new Volunteers:

- Show up
- Pay attention
- Don't become too attached to the outcome

## Module Evaluation – The Role of the Social Worker

Name \_\_\_\_\_ Date \_\_\_\_\_

17. What are some of the services the hospice social worker provides?

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18. How might you recognize that a patient/family would like a visit from the social worker?

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19. Who could you contact if you learned that a patient's wife was really struggling with her conflicted feelings surrounding her children, who weren't being supportive?

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20. What are the five basic life-ending tasks that hospice patients may want to complete?

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5. What are a few ways that volunteers can help relieve family stressors?

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Please note what you found most interesting during this module.

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Please describe any challenges or difficult issues that arose during this module.

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Do you have any suggestions for changes to the course material presented?

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# COMMUNICATION SKILLS

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## Introduction

Communication is defined as an exchange of information between two or more people. It involves sending, receiving interpreting and responding to messages. Communication is one of the most frequent activities we engage in each day. Success in communicating depends on the communication choices we make. It also requires that we be aware of factors, both positive and negative, that can influence how messages are delivered and reacted to by others. Many illnesses impact a person's ability to think clearly, concentrate and express his or her thoughts. This creates a challenge for aides to communicate in a manner that ensures their message is understood. The quality of the aide-patient relationship is significantly influenced by each person's ability to communicate. The effectiveness of communication has a direct impact on quality care and outcomes. In addition to patients, aides communicate with many other people throughout the day. This includes families and other members of the interdisciplinary team. To be effective, aides must be able to adjust the way they communicate based on the unique individuals involved. This is not only impacted by illness, but also by culture, education and past experiences.

## Basics for Being Present



Keep these important things in mind:

1. Show up.
2. Quiet your mind.
3. Listen and truly focus on the person speaking.
4. Keep eye contact, if culturally appropriate.
5. Use a gentle voice tone, except when using a matching tone.
6. Keep an open, attentive posture facing the person.
7. Listen to the words and to the tone. Note the body language.
8. If the person is laughing or smiling while relating pain, remember not to join them in their laughter or smiles.
9. Be patient. Wait for the person to respond to your question or comments – do not rush to fill in silences.
10. Your two most helpful responses will be “*That must be so hard*” and “*What are you feeling?*”
11. If you find yourself talking more than listening, catch yourself and allow the conversation to shift back to the patient’s experience.
12. Let him/her “talk out” his/her story. Many times, if necessary.
13. Don’t attach to the outcome.

## Effective Ways to Communicate with the Patient and Family

The hospice patient and family can be expected to be suffering from shattered reality and from isolation. In either case, the first step toward repair is communication. Communication is *always* two-way; talking into an empty tape recorder is not communication, nor is grimacing into a mirror. But communication does not consist solely of talking and writing. Much is non-verbal.

If the person you wish to help wants to communicate, s/he first needs to feel that you are willing to receive and are receiving his/her communication. Second, s/he needs to feel that you are willing to understand and are understanding his/her communication.

## Convey That You Are Listening

- Observe signals that the person wants to talk (leaning forward, seeking eye contact with you, stealing glances at you).
- Show that you are listening:





- Make eye contact, when culturally appropriate.
- Appropriately nod, smile, gesture.
- Invite the person to talk.
- Allow time for silence and thought. Calm silence is trust building. Try to feel comfortable with silence. Silence is okay.

## **Reassure and Support**

- Train yourself to listen with an unthreatening, non-evaluating, non-comparing attitude.
- Accept the person's right to say, do, and be whatever s/he says, does, and is.
- Be present to the person. Show that you are trying to understand how s/he feels.

## **Active Listening - Learn to Listen and See Behind the Words**

- Communication deals with facts and feelings – words frequently express neither. Half of communication is listening.
- Consider the individuality of the person as s/he experiences, and tries to deal with, his/her needs for attention, acceptance, approval, and affection.
- Note the composure of the person.
- Listen within the framework of the other person's purpose. Seemingly light social conversation may be leading to a concern. It may also reveal just a need for light social conversation.
- Note the external environment. If the TV is on, ask for permission to turn it off.
- Listen as intently to the person's nationality, color, religion, experience, condition, and feelings as you do to his/her words.

## **Responding Effectively**

As much as possible, use the words the speaker uses, but be natural. For example: The patient refers to "my condition." Respond with "your condition" rather than "your lung cancer."



- If words expressing feelings are used, form a question. For example: “You said that \_\_\_\_\_ made you feel alone. Can you tell me more about that?” It is his/her choice whether to expand on the topic or not.
- Particularly when the person is able to speak only in incomplete ideas, repeat back to him/her the gist of what s/he says. This helps him/her to realize how far s/he has progressed with the idea. S/he can then continue, if s/he wants to.
- Instead of saying, “You’re sad,” say, “You’re crying.” Allow the person to express the *feeling* behind the action, if s/he wishes to.
- Ask open-ended questions: “I don’t think I understand. What else could you say about that?”
- If you must ask specific questions, be careful that they are to clarify what the other person wants to communicate...not what you hope s/he is leading up to.
- After a trusting relationship develops: if you hear, “I’m okay” but you notice that his/her hands are clenched, identify it: “Your hands are clenched.” S/he may or may not respond. Confrontation should be used very sparingly, if ever, so say this kind of thing in a very gentle voice.

## Understand that Listening may be Rigorous

Sometimes listening to your patient can trigger your own issues, or be exhausting in other ways. If you find this to be so, it is important to work through your personal feelings with the Volunteer Coordinator and in the Support Group. Unexamined issues that emerge during patient visits can lead to compassion fatigue. Practice techniques to center yourself. When you are centered, you can pay attention more easily to the other person.

We will discuss this further in **Self Care** chapter of this manual.

## Pay Attention

<b>Eye contact</b>	To whom or where does s/he look?
<b>Posture</b>	Does s/he look tense, relaxed, nervous, controlled?
<b>Voice</b>	Does s/he speak softly, slowly, haltingly, or rapidly? Does s/he stay on topic or ramble? Can s/he talk about the details of the topic?
<b>Gesture</b>	Are his/her hands waving wildly or is s/he moving slowly and cautiously?
<b>Demeanor Mood</b>	Is s/he nervous, quiet, controlled, calm, fearful, or angry?

## Allow for Silence



Allowing for silence, although sometimes uncomfortable, can be useful for a good listener. The speaker may be getting his/her thoughts together and thinking about his/her feelings or experiences. The speaker will often, in some way, let you know whether s/he wants the silence. Be aware of eye contact, facial expression, and posture for clues.

On the subject of silence, novelist and essayist, Pico Iyer wrote:

We have to earn silence, then, to work for it: to make it not an absence but a presence; not emptiness but repletion. Silence is something more than just a pause; it is that enchanted place where space is cleared and time is stayed and the horizon itself expands. In silence, we often say, we can hear ourselves think; but what is truer to say is that in silence we can hear ourselves not think, and so sink below ourselves into a place far deeper than mere thought allows.

**In silence, we might better say, we can hear someone else think.**

## Understanding

It is important not only for the listener to understand what the patient is saying, but also for the patient to feel that the listener understands him/her, is concerned, and wants to help. Paraphrasing, clarifying, and reflecting are methods of insuring that you understand the patient, and also, that you can communicate that understanding.

**Paraphrasing** When paraphrasing, the listener repeats what the speaker said, using similar words to those of the speaker. It is often a way to respond to the speaker, letting him/her know that you are listening, while at the same time not leading him/her in any particular direction.

**Example:** Patient: "I'm feeling really lonely now. Nobody seems to care."  
Listener: "I hear that you are feeling alone and no one seems to care about you."

**Clarifying** There are several ways to clarify. The listener can make a guess regarding the basic message and ask if this is correct.

**Example:** Listener: "I understand you to say \_\_\_\_\_. Is that correct?"



Or the listener can ask for clarification when confused about what the speaker has said.

**Example:** Listener: “I’m unsure of what you mean when you say \_\_\_\_\_. Could you tell me more about that?”

### Reflecting

Reflecting is used to try to understand the speaker’s feelings in the context of his/her experiences. The listener tries to go beyond the actual words of the speaker in order to verbalize the speaker’s feelings. This is a delicate process and must be done tentatively so that the speaker is able to disagree with the listener’s input. Reflection is not utilized to guess at what the patient is feeling, but rather to draw from the content of what s/he is saying his or her tone and attitudes. Reflecting allows the listener to focus on feelings in addition to verbal content, make vague feelings clear, and assist the speaker in owning his/her feelings.

**Example:** Listener: “You are smiling, but I sense that you are feeling sad.”

### Leading

Leading encourages open communication. The listener responds to the speaker with an appropriate, encouraging remark that helps the speaker explore his/her feelings and elaborate on them. It also allows the speaker to respond in a variety of ways and encourages him/her to take an active role in the exchange, and retain primary responsibility for the exchange. There are several ways of leading.

#### Indirect leading:

*Indirect leading* is used to get the speaker started.

**Example:** Listener: “Tell me more,” or “How did you feel?” or “Hmm-hummm,” or “And?” “So?” “Then?” or “Give me an example.”

The listener’s non-verbal cues can also be a form of indirect leading. Leaning forward, eye contact, gestures that indicate to the speaker that s/he should proceed may also facilitate the process.

**Direct leading:** *Direct leading* focuses on a topic more specifically.

**Example:** Listener: “Tell me more about \_\_\_\_\_.” “How did you feel when your spouse said that?”

## Focusing

The listener deliberately focuses on a particular aspect thought to be important. That is useful when the speaker is rambling – it may be helpful to reduce his/her confusion and yours. This may be done by using your own feelings of confusion to focus on an important area for discussion.

**Example:** Listener: “I’m confused about \_\_\_\_\_. Could you be more specific?”

## Questioning

Always try to use open-ended questions because they will yield more information and afford more of an opportunity for the speaker to talk.

**Example:** Listener: “How do you feel about \_\_\_\_\_?” “How are things going for you?” or “What has been happening since we spoke last?”

## Summarizing

When summarizing, the listener tries to tie together several ideas and/or feelings at the end of the discussion. Summarizing helps the speaker to see issues in a larger context.

**Example:** Listener: “You’ve been talking about how your friends are feeling. They’re not really talking a whole lot, although you seem to sense they are supportive. You seem to feel that they just don’t know what to say to you or do for you. Does this fit?”

## Closed Questions May Stop Communication

In some cases your listener may respond to a closed statement just because s/he wants to correct what you said. But generally a closed question or statement does not further communication. For example:

- “You seem tired / sad / angry today. Is that true?” “Yes.” And the person does not elaborate, so the conversation stops there.
- “Aren’t rainy days sad?” “Yeah, I hate the rain.”

- “Oh! You’re watching Bonanza! Did you watch this show when it was on originally?”  
“Yes.”

## **Roadblocks to Open Communication**

Avoid any of these responses to your patient or caregiver:

- Yes/No questions.
- Ordering, directing, and commanding.
- Warning, threatening.
- Moralizing, preaching, “should” and “oughts.”
- Advising, giving solutions or suggestions.
- Lecturing.
- Judging, criticizing, disagreeing, blaming.
- Name-calling, labeling, stereotyping.
- Interpreting, analyzing, diagnosing.
- Probing and interrogating.
- Withdrawing, distracting, sarcasm, humoring.

## **How to Know when You are on the Right Track**

The patient may give you a subtle sign, even if s/he is not fully conscious. There may be:

- A smile – sometimes a secret smile.
- A welling up of tears.
- Slowing of breath.
- The return of color to the face.

## **How to Know when You are Off Track**

Whether the patient is fully conscious or not you may see:

- An expression of tiredness.
- A negative response.
- A tensing up.
- A quickening of breath.
- A holding of breath.
- No response.

## **How to get Back on Track**



If the patient is conscious, you may ask the patient for clarity:

- Ask the patient what is happening now.
- Ask if there is something that the patient needs to do.
- Invite the patient to do what s/he needs to do now. “Would you like me to have Susan come in so you can tell her what you just told me?”

## Building Rapport

Building rapport builds trust and deepens the relationship you have with your patient and his/her family members. Be yourself. Be ordinary. Take time to settle in. Let the person take your measure. This is a relationship; it cannot be one-sided.

- Place yourself at the same level as the person you are visiting. Sit down, if they are sitting or lying in bed.
- Offer the opportunity for privacy and uninterrupted time for unhurried discussion. Several brief discussions may be better than a single, lengthy one.
- Be guided by the patient about how much contact is comfortable. Some people want eye contact or physical touch. Others feel that it is an intrusion.
- Match mood and behaviors by breathing or talking at the same pace, or by sitting in the same position as the person with whom you are building rapport. It creates the feeling that you are the “right kind” of person.
- Find common ground. Explore interests, patient’s preferences in music, patient’s background, etc. Let the patient or caregiver know that you also like that kind of activity.  
“I love big band music, too. I have some on my phone. Shall we listen?”
- Always acknowledge heaviness, sadness, anger, or frustration before you raise any further issues  
“You seem sad today. Has something new come up since I last saw you?”
- Be specific about how you can help and what is going to happen. For example, you can establish a time frame.  
“We’ll try this for the first three visits,” or “I’ll be back again in a week,” etc.
- Notice any opportunities to discuss death and funeral arrangements. Not speaking of death suggests that it is too terrible to be spoken of. It may be easier for members of the family or the patient if you initiate such topics.  
“You have so much to consider at this time. Have you asked the nurse what the end stages of this disease may bring about?” “Yes, Thelma certainly seems worse today. Have you thought at all about the final arrangements? What do you think you want to do then?”
- Be respectful. Helpers are ideally consultants who enter the lives of others with great respect.

- Recognize signs that the person is at ease. For example, s/he may match some expression, word, laughter, movement, or posture of yours. Or the person may express agreement verbally. You may then “lead” by making a suggestion, guiding the conversation, or asking a question about a difficult issue.

“This picture of you and your husband is so lovely! Tell me about it.”

## Building Rapport with Someone Who is Semi- or Unconscious

You have important work to do when your patient is in a non-verbal state, whether the patient has a diagnosis of dementia, or another medical diagnosis that precludes his/her ability to communicate. Simply sitting in silence beside your patient is a great gift, but you need to build rapport with the person at that moment so the gift can be received.

Be sure you are centered. Take a deep breath, shut your eyes momentarily, and go within to be certain that you are calm. If you feel anxious, just sit in silence until your own gentle breathing can calm you. This is a time to be gentle and reverent. When you are ready, do some of the following:

- Say the person’s name:
 

“Mrs. Thomas,” or “Good morning, Sam.”
- Identify yourself:
 

“I am Sue Jones. I am a hospice volunteer, and I have come by to see you.” “I am Harry, the hospice volunteer who visited with you last Sunday.” (*Look for special notes for when “Hospice” cannot be discussed*)
- Do not shout, “Can you hear me?” or touch the patient to get recognition. If the patient is drifting toward death, you do not want to call him/her back.
- Demonstrate that the patient’s state is alright. You might say:
 

“I know it is hard for you to respond. That is OK. I will be here for a while with you. We will continue to make sure you are comfortable.”
- Look for non-verbal signs of pain and/or agitation. Watch for grimacing, frowning of the brow, clenching hands into fists, picking at the air or at fabric. This always requires follow up with the facility staff/on call hospice nurse.
- When you must leave, notify the patient of it even if s/he seems semiconscious or unconscious:
 

“Mrs. Thomas, this is Sue Jones. I have been here with you for a while. I am going to leave now but you are in good hands. I will be back again at (time or day). Good bye.”

## Recognizing Cultural Differences in Communication

**“Culture refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.”** - Laurie Andersen, PhD, et al., “Culturally Competent Healthcare Systems,” *American Journal of Preventative Medicine* 2003; 24 (3S): 68-79, 2003





A family's cultural heritage may determine the manner in which they speak, as well. Some cultures speak in a more excited tone of voice and/or use many hand gestures while talking; other cultures are more restrained. When a person from the former group is trying to communicate with a person of the latter group, they each will have to filter the content of the message from its method of delivery. The person who tends to speak in an excited way with many gestures may feel that the other person is cold and indifferent, while the more reserved party may not be able to understand the message because it comes with too many distractions.

### Examples:

- Shaking the head in a horizontal direction in most countries means “no”, while in India it means “yes”; in Hindi language, the voice lowers in pitch at the end of a question.
- In Vietnam, do not touch someone's head or shoulder. Also, do not pass things over someone's head.
- Depending on culture, a patient may not express how much pain s/he is in. Or, it may be culturally appropriate for the patient to express pain more forcefully.
- In some cultures, crying (even wailing) a lot is appropriate. Other cultures might value silence.
- Regarding the body of the patient, there are many different cultural beliefs about what is and isn't appropriate right after death.

## Difference between being a Hospice Volunteer vs being a Friend

**When you visit your patient, understand that your presence as a volunteer has been orchestrated as part of the hospice medical plan of care. It is a professional commitment.**

Should the patient no longer qualify for hospice and come off service, issues related to attachment become immediately apparent. Were you not a hospice volunteer and were simply a friend, you would continue to visit the patient, as per usual. However, as a hospice volunteer, and part of the hospice team, you would need to stop visiting, as the rest of the hospice team has. Long term involvement with patient/family can blur your understanding of your involvement, and needs to be processed in the monthly Support Group, and with the Volunteer Coordinator. Don't confuse your own needs with those of the patient.

### **DON'T:**

- Impose your personal views and values (sometimes religious).
- Give advice. **Do** support the patient and family to make their own choices.
- Go beyond the limits of the plan of care – staying longer, going earlier, making extra visits.
- Misconstrue your visits: You are a hospice volunteer, and the relationship is a professional commitment.
- Continue to visit if the patient has been discharged from hospice.

## Self-Disclosure



Self-disclosure is the process of sharing your private thoughts and feelings with another person. The purpose of self-disclosure is to help the patient/caregiver further explore his/her feelings, thoughts, and actions. This is different from a friendship, where disclosure tends to flow naturally. The volunteer's self-disclosure can be an effective model for the patient's self-exploration, but it must be used sparingly and with great care. In making a decision to disclose something, the volunteer needs to consider the following:

- The reason for self-disclosure must be based on the needs of the patient/caregiver, not the needs of the volunteer. It should be limited.
- There must be a strong relationship between the two.
- The appropriateness of self-disclosure at this particular point in the relationship—self-disclosure is *not appropriate* during a crisis.

## Setting Boundaries

As a volunteer, there are limits to the support you can provide to the patient and family. When you take on a new assignment, the Volunteer Coordinator will review the expectations that both the family and hospice have with regard to volunteer services. However, there may be times when you feel like you're being asked by the patient or family to do more than you are comfortable doing. When that happens, it's important to feel comfortable to kindly (but firmly) set some boundaries.

Boundaries help people to feel safe; the patient needs to know what s/he can and cannot expect from you. It may feel awkward to let patients or their caregivers know that you can't do something they're asking, but it's important to let them know where the boundary line is. Examples of possible boundary related issues might be:

- A patient or caregiver who requests frequent visits beyond your assignment.
- Requests help in toileting or moving the patient (or doing things that the home health aide or nurse might do).
- Sexually inappropriate comments.
- A patient/caregiver becoming overly revealing

It is imperative that you let the Volunteer Coordinator know if a patient or caregiver oversteps his/her boundaries, so that the team can discuss and reinforce appropriate behavior, and you get the support that you need to do a good job. The Volunteer Coordinator will help you process the issue, identify a proper course of action and follow up with the patient or family member accordingly. Boundary issues are often topics at the monthly Support Group.

## Twelve Ways to Say “No”

It might help to remember these ideas for a day when you have to decline a request:

1. I'm so sorry. We're not allowed to drive patients or families.



2. I wish I could help you out, but I'm overextended right now.
3. The Volunteer Coordinator handles scheduling. Perhaps you might want to give her a call with this request.
4. That's something I'll have to think about.
5. Volunteers aren't allowed to give medications. Maybe you can give "Mary" her meds before you go out to your card game with the girls.
6. Sorry, but I'm already booked. I wish I could help though.
7. Oh - I'm not allowed to toilet your mom. It's not something volunteers are permitted to do. If you have any questions about it, you can give the Volunteer Coordinator a call.
8. I'm sorry, but I can only visit once a week right now. Do you have the Volunteer Coordinator's phone number? You can give her a call with your request or talk to one of the care team members.
9. I have an appointment that day/night.
10. I'm not sure that this is something I can do as a volunteer. Let me check in with the Volunteer Coordinator, and I'll let you know when I make my visit next week.
11. I'm so sorry, but when your wife comes off of hospice service, I won't be able to continue to visit.
12. It's been an honor to spend time with your husband. If he comes back on hospice service, I'll ask the Volunteer Coordinator to reassign me, if possible.

### The Bottom Line for Better Communication

1. Address people by name. "Good morning, Mrs. X." Make sure that you ask what the patient would like you to call him/her.
2. Say what you mean, mean what you say. Let your words, actions, and non-verbal expressions all match so they show how you feel. Respect your own and the other person's right to be unique, different, and human. Value openness and respect privacy.
3. Avoid platitudes and clichés, such as phrases like "I know how you feel," "Everything will be all right," "Things will work out for the best," "You'll feel better tomorrow," etc. You cannot presume to understand another person's circumstances.
4. **Make sure that you say "a good goodbye" at the conclusion of each visit. You're not guaranteed another visit.**

## Journal Assignment: Communication Skills

Many of our hospice volunteers make a deep connection with their patients/families. Write about any challenges you think you may have in remaining within your role as a hospice volunteer versus becoming a friend:



## Module Evaluation – Communication

Name \_\_\_\_\_ Date \_\_\_\_\_

What are the most important components in communication?

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Name a few ways to build rapport with a patient and family.

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What is *active listening*? How does it help the communication process?

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What are some differences between visiting a patient as a volunteer vs as a friend?

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What are appropriate ways to respond to a patient's expression of feelings?

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Please note what you found most interesting during this module.

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Please describe any challenges or difficult issues that arose during this module.

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Do you have any suggestions for changes to the course material presented?

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## Grief and Bereavement

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### Role of the Hospice Bereavement Coordinator

- Identify families at risk for *complicated grief*, and offer pre-bereavement calls/visits. Complicated Grief; Prolonged Grief Disorder Added to the DSM-V as Persistent Complex Bereavement Disorder
  - In the section of Trauma- and Stressor-Related Disorders as one of the “Other Specified Disorders” and in the chapter on “Conditions for Further Study”
  - Complicated grief (CG) is marked by an unusually intense grief experience, lasting well beyond the period expected by social and cultural norms, and is accompanied by impairments in daily functioning.
- Maintain a hospice bereavement treatment plan prior to death, as well as afterwards:
  - Social Worker (or other member of IDT) will make initial condolence call within 1 week of patient death.
  - Follow up call from Bereavement Coordinator or Counselor 4-6 weeks after the death
  - Offer 1:1 visits for bereavement counseling (based upon Bereavement Risk)
  - Offer support, witness, and companionship in the grieving process
  - Parse out the difference between grief and clinical depression with the individual
  - Recommend counseling when needed
  - Refer to our support groups or other appropriate bereavement support groups in the community
  - Supervise bereavement volunteers in their visits with the bereaved
  - Send bereavement mailings over the course of the first 13 months.



## Community Bereavement

- One-to-one bereavement consultation is available to people in the community. They are referred by the Community Clinicians, hospitals, doctors, or self-referral.
- Refer to bereavement groups (as noted above)
- Monthly support group at multiple locations

## Annual Memorial Service

- An interdisciplinary celebration of the lives of our patients.
- Invitations are sent to the bereaved from the past year; the community is welcome as well

## UNDERSTANDING GRIEF AND BEREAVEMENT

### The Terms Used to Describe the Experience of Loss

People frequently misuse the terms used around the loss of a loved one. The proper definitions are:

- *Grief*: The emotional reaction to loss (includes mental, emotional, physical, and spiritual components).
- *Mourning*: The internal, private, or intrapersonal process AND the outward, public, or interpersonal process. Often dictated by cultural or religious norms or rituals. Some cultural or religious mourning practices may include the wearing of black clothes or a black armband, hanging flags at half-mast, shiva, creating altars in Buddhism and Mexican traditions, etc
- *Bereavement*: The state of being deprived of a loved one; made desolate, especially by death. Also the process a person who is dying may feel about one's own impending death and about losing one's capabilities.

### Elisabeth Kubler-Ross and the Dying Process

Dr. Elisabeth Kubler-Ross was a psychiatrist who transformed the way we treat dying patients. She recognized that the patients' psychological and spiritual needs were not being met by the medical practices at that time, which only served their medical needs. Doctors and nurses would not talk with their patients about the process they were going through, leaving the patients feeling isolated and frightened.

In the course of her life's work, Dr. Kubler-Ross learned that people evolve through a series of different emotional states, moving from one to the other, and often back again through the same stage, until they hopefully reach a place of acceptance of their impending death. The Kubler-Ross five stages of dying are: **denial, anger, bargaining, depression, and acceptance.**



## Post Modern Grief Theory

Long gone are the times when we conceptualize grief has having stages, phases, or even a logical path ‘forward’. Research has identified that there are no stages of grief. However, there are numerous ways to make sense of the grief process, which is intrinsically complicated, individual, and forever changes the lives of those who are grieving. Some of which are included below;

- **Dual Process Model** (Strobe & Schute, 1999): A model of grief focused on how the griever copes. Two sets of coping processes that happen interchangeably. This allows for both expressing and controlling emotions. Allows for more flexibility within the grief process. The bereaved move in-between processes.
  - 1. Loss Oriented: grief work, intrusion of grief, coping with the loss
  - 2. Restoration Oriented; attending to life changes, doing new things, and avoiding/distracting one’s self.
- **Task Based Models** (Fox, 1985; Worden, 1991) Moves from grief as ‘passive’ to an ‘active process. Tasks are the active ‘grief work’.
  - Accepting the reality of the loss
  - To experience the pain/emotional aspects of the loss
  - Adjust to the environment without the deceased
  - Relocate the deceased within one’s life & find ways to memorialize them
- **Continuing Bonds** (Klass, Silverman, & Nickmann 1996; Strobe & Schute, 2005). Death ends a life, not a relationship. A continuing bond has been defined as “the inner presence of an ongoing inner relationship with the deceased person by the bereaved individual”. May include holding on to the memory of the deceased by reminiscing, telling stories about the deceased, looking at photographs, keeping possessions, communicating with the deceased through letters, talking, or prayer.
- **Meaning Reconstruction** (Neimeyer, 2000, 2007). Making meaning and sense making that happens when the bereaved searches for ‘why’ and seeks to make sense. Meaning reconstruction can include
  - The attempt to find or create new meaning in life of the survivor
  - The integration of meaning as well as its construction
  - The construction of meaning as an interpersonal as well as personal process
  - The development of preverbal and well as explicit and articulate meanings

## Companioning

Companioning the bereaved is not about assessing, analyzing, fixing or resolving another’s grief. Instead, it is about being totally present to the mourner, even being a temporary guardian of her soul. The companioning model is anchored in the “teach me” perspective. It is about learning and observing. If your desire is to support a fellow human in grief, you must create a “safe place” for people to embrace their feelings of profound loss. This safe place is a cleaned-out, compassionate heart. It is the open heart that allows you to be truly present to another human being’s intimate pain. In sum, companioning is the art of bringing comfort to another by becoming familiar with her story (experiences and needs). Of course this may well involve tears and sorrow and tends to involve a give and take of story. I tell you my story and you tell me yours. It is a sharing in a deep and profound way.



More specifically, for me...

1. Companionship is about being present to another person's pain; it is not about taking away the pain.
2. Companionship is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.
3. Companionship is about honoring the spirit; it is not about focusing on the intellect.
4. Companionship is about listening with the heart; it is not about analyzing with the head.
5. Companionship is about bearing witness to the struggles of others; it is not about judging or directing these struggles.
6. Companionship is about walking alongside; it is not about leading or being led.
7. Companionship means discovering the gifts of sacred silence; it does not mean filling up every moment with words.
8. Companionship the bereaved is about being still; it is not about frantic movement forward.
9. Companionship is about respecting disorder and confusion; it is not about imposing order and logic.
10. Companionship is about learning from others; it is not about teaching them.
11. Companionship is about curiosity; it is not about expertise

## Aspects of Grief

There is no right or wrong way to grieve. All the feelings that a bereaved person feels are normal. It is helpful to know that human grief is a process that often includes a healing pattern. Below is an adapted handout from Hospice of Santa Cruz that is sent to our newly bereaved families:

### **Shock & Surprise**

Even if the death is expected, you may feel numb or anesthetized for several weeks or months afterward. Your actions may be mechanical. You get things done (for example, handle all of the funeral details), but you are not "all there". People around you may be saying "Isn't he strong" or "She's handling this so well". The impact or reality of the death has not fully reached you. This period of shock is your psyche's way of protecting you by allowing reality to set in slowly. If the loss is sudden, unexpected, or violent, the period of numbness may be longer.

### **Emotional Release**

As the shock wears off, reality can be acutely painful. As the full impact gradually dawns, conflict may arise about whether or not to show grief. How much can you share and for how long? You might try to keep up a good front or remain strong, even though you may feel like crying or





screaming. If people are praising you for being so brave and not "falling apart" do you dare show them how you really feel? This is a time when emotional release is important and encouraged. Concealing painful feelings may prolong the grief process and increase physical and emotional distress. At this point family, friends, or a grief counselor can help support your expressions of grief.

### **Loneliness**

Family and friends can be helpful and consoling at first, but may not check in as much as time goes on. The memorial may be the focus for realizing that your loved one is gone. Loneliness, isolation, and depression may begin once the memorial service is over. After the service, you may suffer a second major loss: the loss of everyday contact with your loved one. Your entire routine of daily living may have been shattered. You may be suddenly overcome by an utter sense of depression and despair. It is important at this point to have people in your life who can validate the magnitude of your loss.

### **Anxiety & Physical Distress**

Some questions that may come up for you are the following: What am I going to do? What's going to happen to me? How can I get along without her? and Will I lose my friends? Exhaustion, anxiety, and grief itself may cause physical symptoms such as shortness of breath, insomnia, headaches, backaches, or upset stomach. During the entire grief process, take especially good care of your body. You may feel vulnerable and need a lot more rest. It's not uncommon for those in the early process of grief to come down with more colds or the flu as grief disrupts the body's immune system. See your physician if physical symptoms are serious or persist.

### **Panic & Disorganization**

You may have trouble concentrating on anything but the loss. You may think something is wrong with you. You may replay thoughts such as these: won't they ever stop? Something I think I see her. Sometimes I feel his touch. Sometimes I hear her voice. I've got to do something. I can't sleep or eat. All I do is think about her. Will it ever stop hurting? or Will I ever stop dreaming about him?

### **Guilt**

When faced with real or imagined guilt, you may begin asking yourself questions like these: What did I do wrong? Why didn't we spend more time together? or Why didn't I do more to show him I loved him? These questions and many others may indicate guilt, regrets, or unfinished business. These feelings can be brought to the surface by sharing them with a non-judgmental listener, or in a letter, or journal.

### **Hostility & Anger**

Along with these feelings of guilt, you may experience hostility. Maybe you feel some hostility toward people whom you believe have contributed to your problem. For example, you may feel angry with a physician and wonder why they didn't do something differently. You may be experiencing anger at your friends who draw away from you or seem to belittle your loss with well-meaning but clumsy remarks. You may be furious with God or fate for taking away your loved one. You may also be angry with your loved one for dying and abandoning you. Anger is a



very normal human emotion, and it is important to find ways to feel this emotion and work your way through it, instead of around it or avoiding it. Talking about your thoughts or feelings and engaging in physical activity are both good ways to keep anger from burning inside you.

### **Suffering in Silence & Depression**

This is also a time when you may suffer in silence. You might feel fatigued, worn out, and unable to get started in any activity. Your thought processes are involved with the loss, but you may no longer want to talk about it. You may feel that others expect you to stop grieving. Tears, anger, frustration, and depression may be poorly tolerated by others several weeks after the funeral. You may have feelings of not wanting to go on and then may be shocked or feel guilty for having such thoughts. This is a period where you are recreating meaning in life, and it takes time.

### **Gradual Overcoming of Grief**

Your adjustment to a new status in life gradually occurs by working through this grief period. There can be noticeable changes in the first few months, but often it is much longer. By the end of this phase, there is a considerable brightening of mood, more activity and the beginning of re-establishing connections with people.

### **Readjustment to the "New Normal"**

While the most intense grief may ease in a few months to a year, readjustment can continue for several years. Because traditional symbols of grief such as a black veil or clothing, an armband, or a black wreath on the front door are out of style, it is easy for others to forget that you are grieving. You are beginning to restructure your life without your loved one. You may want to take a vacation, get involved in a new activity, or take up old activities that you used to enjoy. Occasionally, you may feel twinges of guilt as you begin to enjoy yourself or laugh freely again, as though you are somehow betraying the memory of your loved one. It is helpful to be aware of feelings of guilt that get in the way of readjustment. It is also helpful to recognize that wedding anniversaries, holidays, birthdays, or the anniversary date of the death may cause a flood of feelings, or may bring back some of the intensity of grief you felt in the first weeks. These feelings are normal and do not mean that you will be in acute pain forever.

## No Two People Grieve the Same

This is the cardinal rule about grief. And because it is so, no person is qualified to tell another person how to grieve. Each individual has his/her own methods of coping, and his/her own time schedule for how to deal with the impact the loss has had on him/her.

Typically the gender of the person, their age, their cultural background, and the number of losses they have experienced all affect how they cope with the loss of a loved one. Men may be more action-oriented around a loss. They may be the Executor of the estate, handle the arrangements for the funeral, the plot, the headstone...all outgrowths of days when it was the men who dug the grave. Women may tend to the more spiritual and emotional aspects of the process.

It can be helpful for children to be given an opportunity to take part in the rituals. A simple determination of their interest can be obtained by describing what will take place and asking them how they feel about it. Children will sometimes astound adults by their ability to take part in vigorous play even after a very recent loss. This does not mean that they don't feel the loss or don't



care. They simply need to be able to let off steam, then express their loss as the feelings come to the surface, and then resume their activities.

## The Role of the Hospice Volunteer around Normal Grief

Grief is so closely intertwined with the whole hospice experience that it would be impossible to segregate it out as a separate entity. So, as a volunteer in this situation, you simply do all the same things you do whether the patient or the family is showing signs of grieving or not: you listen, you affirm that their feelings are normal, and you simply are there for them. To reassure you about the numerous feelings that are considered “normal,” a list follows.

- Is there a right way to grieve? Why do I feel out of control?
- I’m so glad it’s over.
- I never knew it would hurt so badly!
- I feel so relieved.

These grief responses are all natural and normal. It is important to reach out and talk with people and to cry with them when you need to. Here are some additional normal reactions:

- I feel as if it isn’t real.
- I feel a tightness in my throat and a heaviness in my chest.
- My mood changes over the slightest things; I cry at unexpected times.
- Sometimes I feel angry.
- I don’t want others to see me when I feel sad.
- I can’t concentrate.
- I sense my loved one’s presence, like hearing his/her voice.
- I feel like my mind is on a merry-go-round that will not stop.
- What is there left for me to live for? I have an empty feeling.
- I have trouble sleeping (or I sleep too much).
- I don’t feel hungry (or I’m eating all the time).
- I miss being touched.
- I miss having someone around to help me make decisions.

## Homework Assignment: The Five Wishes

Fill out the Five Wishes document for yourself (located in the front pocket of this manual).

When you complete your own *Five Wishes* document, talk about your wishes with your family members (especially your health care proxy), give a copy to your doctor, and let everyone in the family know where you keep your copy.

Try to really think through all the questions and answer as if you were a hospice patient with less than six months to live.

## Journal Assignment: Grief and Bereavement

Write about your experiences of losing a loved one:

- How did you experience this loss? Physically? Spiritually? Emotionally?
- Did your feelings change over time? In what ways?
- What was helpful to you during the time you were acutely experiencing loss?
- What was not helpful?

## Readings on Grief and Loss

Cacciatore, Joanne. (2017). *Bearing the unbearable. Love, loss, and the heartbreaking paths of grief*. Wisdom Publications.

Devine, Megan. (2017). *It's OK that you're NOT OK*. Sounds True.

Didion, Joan. (2005) *The Year of Magical Thinking*. New York: Alfred A. Knopf.

Doka, Ken. (2017). *Grief is a journey. Finding your path through loss*. Atria Books.

Miller, Sukie. (1999). *Finding hope when a child dies. What other cultures can teach us*. Simon & Schuster.

Shurrman, Donna. (2003). *Never the same. Coming to terms with the death of a parent*. New York. St. Martin Press.

Warner, Jan. (2018). *Grief day by day. Simple practices and daily guidance for living with loss*. Althea Press.

Wolfelt, Alan (1992) *Understanding Grief; Helping yourself heal*. Muncie, IN Accelerated Development.

Wolfelt, Alan (1997) *The Journey Through Grief*. Ft. Collins, CO. Companion Press.



## Module Evaluation – Bereavement

Name \_\_\_\_\_ Date \_\_\_\_\_

What are some of the services Tufts Medicine Care at Home offers for bereavement support?

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What are some of the ways that volunteers can provide bereavement supports?

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Name three common secular or religious mourning rituals.

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Name four different responses one might have to grief (physical, emotional, spiritual, etc.)?

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## Homework Assignment: Understanding Spiritual Care

Before you read this chapter, please write about what you think the Chaplain does in hospice:



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# SPIRITUAL CARE

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Hospice has always included a spiritual dimension to the care and comfort of patients and families. Although the meaning of “spiritual care” may seem elusive to many clinicians, acceptance of its significance and role in the care of patients at the end-of-life has grown as the hospice industry continues to develop its standards of practice. As Keith Meador wrote... “There is no substitute for time to do the work of a ‘good death.’ While the interpretation of a good death may vary by tradition and culture, most consider the opportunity for a good death to include adequate pain management and time to make peace with one’s neighbor and with God while supported emotionally by family or friends. Adequate spiritual care helps provide the context for such a death...” (Meador, 2004)

## Chaplain as Part of the Hospice Interdisciplinary Team

The Centers for Medicare and Medicaid Services (CMS) mandates a professional spiritual caregiver to be a core member of the hospice interdisciplinary team. Within this team, the hospice chaplain is part of a group of medical professionals who monitor and manage the pain and comfort of the whole person, including the physical, emotional and spiritual aspects of the patient’s life. Chaplains are part of an important team of professionals who have been given the duty of assisting individuals and family members at one of the most important times of life, the person’s death. Spiritual counseling is one component of the *Counseling Services* standard, as mandated within the Hospice Conditions of Participation (§418.64, d). This standard requires that the hospice provide as a core service:

- Bereavement counseling
- Dietary counseling
- Spiritual counseling

## Responsibilities of the Hospice Chaplain

The primary responsibilities of the hospice chaplain include:

- Performing initial and ongoing spiritual assessments on hospice patients and families
- Providing spiritual support to patients and families
- Serving as a core member of the hospice interdisciplinary team
- Assisting in the establishment of the patient’s hospice plan of care, recertification plan, and discharge plan
- Coordinating visits and serving as a liaison with community-based clergy, experts and resources specific to the patient’s faith and beliefs
- Praying with and counseling patients and families
- Administering sacraments at the bedside
- Holding chapel services
- Supporting the bereavement process

- Serving on the hospice’s ethics committee and assisting with ethical decision-making
- Participating in quality assessment and performance improvement activities
- Supporting hospice employees during times of stress, burnout and crisis

## Qualifications of the Hospice Chaplain

In understanding the qualifications of the hospice chaplain, it is first important to know the difference between a pastor and a chaplain.

- **Pastors** are leaders of local churches and usually perform duties associated with their church and denomination.
- **Hospice chaplains** are specially trained healthcare workers who tend to the spiritual needs and beliefs of a variety of individuals.

The similarity of these needs is the presence of a terminal illness. Whereas the pastor needs to be familiar with a limited number of religious beliefs and practices, a chaplain must be familiar with a wide range of religious and spiritual expressions.

## Standards of Spiritual Care

The Joint Commission states that the professional who addresses the spiritual needs of patients in the healthcare environment should be *Culturally Competent*. Cultural competence is particularly important in the hospice setting, since different cultures have different views on spirituality and religion. For example, a devout Catholic patient from the Philippines will have a strikingly different view of religion and spirituality than a Native American patient who may take his or her spiritual strength from nature, in addition to or separate from a formal religious tradition. (Joint Commission, 2005). The Joint Commission concludes that individuals who tend to the spiritual needs of patients should understand that there are many different spiritual and religious perspectives. Hospice Chaplains should have an ability to focus on the spiritual issues of patients without forcing their own beliefs on them.

## Education and Competencies of Hospice Chaplains

The National Hospice and Palliative Care Organization (NHPCO) defines the qualifications of the chaplain or spiritual counselor as an “individual with appropriate clergy education, experience and skills to relate to pastoral counseling and bereavement support.” The commonly accepted educational standard for clergy education is a Masters of Divinity degree. To be effective, hospice chaplains should:

- Possess a personal spirituality that allows sensitivity to the feelings of the terminally ill and their families, both before and after the patient’s death
- Have the ability to apply knowledge of the grief and death and dying process when providing spiritual care to hospice patients and families
- Be able to communicate effectively with people of all socioeconomic backgrounds
- Be able to make generalizations, evaluations or decisions based on sensory or judgmental criteria
- Demonstrate evidence of patient advocacy



- Be skilled in pastoral care and bereavement counseling

## The Concept of Spirituality

The term “Spirituality” comes from the Latin word, *spiritualitas*, meaning “breath.” The concept of spirituality has been identified to include five main attributes:

- **Meaning**, which refers to the significance of life or the ability to make sense of life situations.
- **Value**, which includes beliefs and standards that are cherished by a person.
- **Transcendence**, which involves experiences and appreciation of life and existence beyond the person.
- **Connecting**, which involves the person attempting to unite with a higher power.
- **Becoming**, which includes an unfolding of life that demands reflection and experience.

Exploring these five attributes as part of the spiritual assessment and care plan can provide the necessary support to allow an individual to cope with the crisis of advanced illness and the fear and uncertainty of death.

## Importance of Spiritual Care to Hospice Patients

Spiritual care is of utmost importance to most hospice patients and the family members who care for them. To appreciate the importance of spiritual care, the chaplain must understand the meaning of spirituality. Simply stated, spirituality is an intangible part of human existence that is found in the core of a person’s being. It is defined as however a person chooses to define it, but it always means something good and sacred to the person. The Joint Commission states, “Spirituality can be defined as a complex and multidimensional part of the human experience—our inner belief system. It helps individuals to search for the meaning and purpose of life, and it helps them experience hope, love, inner peace, comfort, and support.” (Joint Commission, 2005). Another way to understand spirituality is to recognize that human beings have self-knowledge, or knowledge of their own existence. Existence is measured in the form of time and relationships. Time includes the present, past and future. Relationships involve the important people in a person’s life, including children, spouses, partners, parents, siblings, friends and God. Life lived in real time and with the presence of others helps define the person’s existence and spirituality.

## Religion and Spirituality

**Religion** may be defined as “an institution with certain beliefs and rituals and a history shared by a community of observant and faithful members” (Holder, Clanton, 2004). Common religions include Judaism, Christianity, Buddhism, Hinduism, and Islam. In contrast, **spirituality** has come to mean a personal engagement with whatever is sacred or transcendent in life. The transcendent component of spirituality refers to going beyond a prior form or state. Spirituality usually involves a belief that there is more to life than what is evident on the surface. It is an activity of seeking deeper meaning in oneself, in relationships, or in life. Spirituality may or may not involve religion. For some people, spirituality refers to their religious faith. For others, it may mean an individual and personal sense of what is ultimate and sacred in their lives. Religion and religious practices often enhance, inform, and assist in an individual’s spirituality. However, the



core elements of spirituality are generally present whether a person is actively religious or not. Because each person grasps the concept of spirituality uniquely, the spiritual counselor needs the ability to embrace the widest possible meaning of the “spiritual” without influencing individuals to particular beliefs or practices. Eventually, most people will confront a spiritual search as he or she addresses the meaning of life’s end and the ultimate loss of death.

## Spiritual Pain

One of the primary responsibilities of the hospice interdisciplinary team is to manage the patient’s pain at the end-of-life. In managing pain, it is important to recognize that the intense suffering by dying patients and their families involves “total pain,” which includes physical, social, psychological, and spiritual pain. Spiritual pain may involve:

- Loss of meaning and hope
- Loss of identity due to lost roles, lost activity, and lost independence
- Anger at God and a sense of betrayal or abandonment by God
- Disruption in one’s faith system
- Fear of God and punishment
- Need for reconciliation and forgiveness

Patients experiencing spiritual pain may exhibit signs of spiritual suffering, including:

- Physical symptoms of pain
- Insomnia
- Withdrawal or isolation from others
- Anxiety, fear and mistrust
- Anger
- Depression
- Guilt and low self-worth
- Hopelessness
- Despair

## Spiritual Crisis

When patients are told that their existence is threatened, they may undergo a spiritual crisis, or what is called by theologians and philosophers as an *Existential Crisis*. The patient’s inner being is compromised, much like a medical illness compromises physical health. At such times, people begin to examine who they are. This self-examination takes place as they think about the immediate crisis and its threat to their present existence. The person questions:

- “How long will I be able to: ... remain independent? ...drive my vehicle? ...manage my normal routine?”
- “Will the pain begin to control me or can I control it?”
- “Will I remain conscious and able to talk with my friends and family?”

People experiencing a spiritual crisis tend to contemplate how the illness threatens their future. Questions concerning unfinished business become important, including:

- “Is there anyone I need to talk to, see, or make peace with before I’m gone?”
- “Where am I going when I’m gone?”
- “What will the other side be like?”
- “Is there really another side?”

## Consolidating the Past with the Present

The past is an important part of a person’s existence. The older a person is, the more important it is to consolidate the past with the present. This is commonly done by telling stories about past experiences. Oftentimes, these past stories are repeated by the person over and over to anyone who will listen. The repetitiveness may make the person appear to have cognitive problems, although in most situations, the repetition of past experiences is the individual’s integration and affirmation of their existence. It is a way of defining who they are. Such are the subjects of a person’s spirituality. Who they are. Who they were. Who they will become despite their illness. Spiritual care becomes critically important, because it concerns the core of a person’s being.

## Comprehensive Spiritual Assessment

The Medicare Conditions of Participation (§484.64,d) specify that the hospice must provide an assessment of the patient’s and family’s spiritual needs. This is initially done at the start of care by the registered nurse as part of the initial comprehensive assessment. If the initial comprehensive assessment identifies the need for spiritual care, a spiritual assessment must be completed within five calendar days and updated as the patient’s needs change. The main goal of the spiritual assessment should be to identify the patient’s needs, hopes, resources, and possible outcomes regarding spirituality and determine appropriate actions necessary to address those issues. Best practices specify that the spiritual assessment should include a review of the patient’s religious affiliation (if any), as well as any beliefs or spiritual practices that are important to the patient. This assessment is critical to identifying how patients wish to utilize spiritual or religious beliefs in their hospice care. Two common models have been used to guide spiritual assessments. The HOPE model (Anandarajah & Hight, 2001) provides four domains that cover basic areas of inquiry for conducting a spiritual assessment:

**H:** Sources of hope, meaning, comfort, strength, peace, love, and connection

**O:** Organized religion

**P:** Personal spirituality and practices

**E:** Effects of spirituality on medical care and end-of-life-issues.

The purpose of the HOPE model is to determine the patient’s spiritual support systems, religious affiliations, and personal spiritual practices, as well as ways in which the chaplain’s understanding of the patient’s spirituality can improve care.

The FICA model (Puchalski & Romer, 2000) is also commonly used to support the spiritual assessment. It includes four areas:

**F:** Faith or beliefs. The chaplain asks, “What is your faith or belief?”

**I:** Importance and influence. The chaplain asks, “Is your faith important in your life?”

**C:** Community. The chaplain asks, “Are you a part of a spiritual or religious community?”

**A:** Address. The chaplain asks, “How would you like me to address these issues in your care?”

The FICA model provides useful questions for determining the role of religion or spirituality in the patient’s life.

## Medicare-Covered Spiritual Counseling

Medicare covers spiritual counseling for the purpose of training the patient’s family or other caregiver to provide care, and for the purpose of helping the patient and those caring for him or her to adjust to the approaching death. Counseling services may be provided to hospice patients within all levels of hospice care. In patients receiving hospice services in a nursing home or inpatient facility, the hospice is responsible for furnishing counseling services in these settings. If the spiritual assessment identifies spiritual needs, the hospice plan of care must include interventions to manage these needs. It must also include the scope and frequency of chaplain services, along with measurable goals anticipated from implementing and coordinating the plan of care. This plan should be reviewed and revised as necessary no less frequently than every 15 days. Spiritual counseling must be coordinated with other core and non-core services provided to the patient, and documentation within the clinical record should clearly support this coordination.

## The Goal of Spiritual Care in Hospice

When the hospice chaplain understands what human spirituality is, then the chaplain’s role and purpose on the hospice team becomes clear. The goal of spiritual care is to assist the patient to find comfort through his or her spiritual resources. The hospice chaplain does not come to the patient relationship with ready answers and resources. Instead, the chaplain listens for the evidence and issues of the patient’s spirituality and uses what the patient already has to provide comfort. Many times the hospice chaplain will find similarities between what gives the patient spiritual comfort and what gives the chaplain spiritual comfort. When these mutual interests are discovered, the work of the hospice chaplain seems natural and a great rapport is often developed between the patient and the chaplain.

## The Chaplain as a Spiritual Agent

Hospice work is always focused on the patient. As the chaplain discovers what is spiritually meaningful to the patient, it is the responsibility of the chaplain to assist the patient to find comfort in and through the person’s spirituality. Sometimes this means that, with the patient’s permission, the chaplain will contact a clergy member or spiritual authority more closely

connected with the patient’s spirituality. At such times, the primary responsibility of the hospice chaplain is to monitor the patient’s spiritual care and assist the patient’s spiritual caregiver with general information about the hospice process and purpose. However, the chaplain must always be cognizant of the requirements for patient privacy (e.g., HIPAA regulations). Spiritual comfort is an important resource of comfort for the hospice patient and his or her family. The chaplain’s role and function on the hospice team is to discern what spiritual resources the patient has and assist the patient in using them for personal comfort.

### Spiritual Resources

In order for the chaplain to help hospice patients to use spiritual resources as a comfort measure in managing their illness, the chaplain must discern what spiritual resources each patient has and how the hospice can support any identified deficits. The chaplain has two primary diagnostic tools in discerning spiritual resources. First is the chaplain’s professional presence with the patient and family. And second is the chaplain’s professional knowledge of the essential characteristics of spirituality and the various ways it is expressed. The hospice chaplain’s non-threatening, face-to-face presence with the patient and family is perhaps the most useful tool the chaplain has in coming to an understanding of the patient’s spiritual resources. Taking time to empathically understand the circumstances that have led to the patient’s admission to hospice is a good first step in building trust. Asking open-ended questions about the patient’s condition helps the patient express his or her self. Honestly answering the patient’s questions also helps establish a positive rapport, although the chaplain must be careful to keep the discussion patient-focused.

## The Role of Volunteers – What Can You Do?

“Holy Listening and Holy Curiosity”

- Holy Listening – being open to the spiritual dimension of your interactions. The gaps and connections
- Holy Curiosity
  - Be willing to ask questions about a patient’s “mysteries”
  - Acknowledge feelings.
  - Respect beliefs and experiences
- Pray with them, if they/you are willing
- Encourage them to call their church
- Encourage them to call the Chaplain or ask if you can call the Chaplain for them

<b>RELIGION AND END OF LIFE CARE</b>		
<b>Christianity</b>	Christians believe Jesus is the Messiah or Christ. Jesus’	<b>Catholic</b>



<ul style="list-style-type: none"> <li>• Catholic</li> <li>• Orthodox</li> <li>• Protestant</li> <li>• Others (e.g., Church of the Latter-Day Saints, Jehovah’s Witnesses, etc.)</li> </ul>	<p>death was a means of atonement for the sins of men and women, a way to experience the forgiveness of God.</p>	<ul style="list-style-type: none"> <li>• Anointing of the sick is conducted only by a priest before the person’s death.</li> <li>• Other sacraments include reconciliation (formerly called confession-conducted only by a priest) and Holy Communion (which can be conducted by a priest or his designate). In reconciliation the person asks for forgiveness and is reminded of God’s love. Holy Communion includes a small piece of bread representing the communion of the individual with Christ.</li> <li>• Funerals are generally held 2-3 days after death.</li> <li>• Mass may be held on the anniversary of the person’s death.</li> </ul> <p><b>Orthodox</b></p> <ul style="list-style-type: none"> <li>• Last anointing may be conducted before or after death.</li> <li>• Confession and Holy Communion are important rituals and are conducted by priests.</li> <li>• A memorial service is held on the closest Sunday to the 40<sup>th</sup> day after death.</li> <li>• Widows avoid social activities for one year.</li> </ul> <p><b>Protestant</b></p> <ul style="list-style-type: none"> <li>• There are no last rites. Prayers are given to offer comfort and support.</li> <li>• Anointing of the sick is accepted by some.</li> </ul>
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		<ul style="list-style-type: none"> <li>• Some Pentecostal and charismatic churches believe in faith healing.</li> </ul> <p><b>Others</b></p> <ul style="list-style-type: none"> <li>• Church of Jesus Christ of Latter-day Saints (Mormons) will administer a sacrament if the patient requests.</li> <li>• Jehovah’s Witnesses do not believe in sacraments.</li> <li>• Jehovah’s Witnesses will be excommunicated if they receive a blood transfusion.</li> <li>• Christian Scientists rely mostly on spiritual healing rather than medical interventions. It is unlikely they will seek medical help to prolong life.</li> </ul>
<p><b>Islam</b></p>	<p>Islam means submission. Muslim means one who submits. A Muslim is one who submits to Allah. The founder of Islam, Mohammad received a vision while meditating. This vision later became the Qu’ran or Koran. Mohammad espoused the Five Pillars of Islam:</p> <ul style="list-style-type: none"> <li>• Confession of Faith daily in front of witnesses.</li> <li>• Prayer five times a day.</li> <li>• Fasting during the month of Ramadan.</li> <li>• Almsgiving.</li> <li>• Pilgrimage to Mecca. Beliefs important to end of life care include belief that Allah is the creator, controller, and governor of the universe. Fear,</li> </ul>	<p>Diet and Fasting</p> <ul style="list-style-type: none"> <li>• Pork, bacon and ham are forbidden.</li> <li>• Alcohol is forbidden, even in cooked products.</li> <li>• Beef, mutton and poultry must be halal (killed and prepared under Islamic law).</li> <li>• Fasting during Ramadan is not required of the sick.</li> </ul> <p>End of Life Care</p> <ul style="list-style-type: none"> <li>• Second-degree male relatives (e.g., cousins or uncles) should be the contact person. They will determine whether the patient and/or family</li> </ul>



	<p>doubt and pain are seen as a lack of belief in Allah.</p>	<p>should be told about diagnoses, tests, prognoses, etc.</p> <ul style="list-style-type: none"> <li>• Patients may choose to face Mecca (west or southwest in the U.S.). The head should be elevated about the body.</li> <li>• Discussions about death are not usually welcomed.</li> <li>• Stopping medical treatment is viewed to be against Allah’s will.</li> <li>• Grief may be expressed through slapping or hitting the body. Grief counseling is not well accepted.</li> <li>• If possible, only a same sex Muslim should handle the body after death. If not possible, non-Muslims should wear gloves so as to not touch the body.</li> </ul>
<p><b>Judaism</b></p>	<p>Judaism began when the descendants of Abraham’s grandson, Israel, were enslaved in Egypt. Moses led them to the promised land after 40 years of wandering through the desert. During this time, Jewish law was divinely revealed to Moses. The law is known as the Torah.</p> <ul style="list-style-type: none"> <li>• The Sabbath is celebrated from sunset on Friday to sunset Saturday evening. Sabbath is a day of rest. Orthodox Jews may not</li> </ul>	<p>Diet and Fasting</p> <ul style="list-style-type: none"> <li>• Observant Jews wish to eat only kosher foods. Kosher foods have been prepared under strict guidelines for how animals are slaughtered, separating milk and meat, and avoiding certain foods such as pork and some seafood. An alternative might be a vegetarian diet if kosher foods are not available. A rabbi may assist with finding sources for kosher meals if these are not available.</li> <li>• During Passover, leavened bread is avoided.</li> </ul>





	<p>turn off or on lights or other appliances.</p> <ul style="list-style-type: none"> <li>• The degree to which a Jew observes Sabbath and other rituals is related to whether they are orthodox, liberal or conservative.</li> </ul>	<p>End Of Life Care</p> <ul style="list-style-type: none"> <li>• Everything must be done to prolong life. No actions to hasten death are permitted. Thus, the patient on life support systems may remain on these until death.</li> <li>• A dying person should not be left alone. A rabbi’s presence is desired.</li> <li>• After death, the body is placed on the floor, with the feet towards the door, and covered with a sheet. A candle is placed near the head. The body must not be moved on the Sabbath if at home.</li> <li>• A special association called Chevra Kadisha conducts purification of the body.</li> <li>• Autopsy and cremation are forbidden.</li> <li>• The funeral is usually held the day after death. The family then mourns for 7 days (called “Shiva”). Mirrors are covered, men do not shave, and family members wear a black ribbon. Mourning continues for 30 days.</li> </ul>
<p><b>Hinduism</b></p>	<p>Hindus believe in multiple gods and goddesses, with one great spirit, Brahman. Karma is the working out in this life of events that occurred in a previous life. Reincarnation is a strong belief. The Hindu hopes to live a good life so they may become one with Brahman. Hindus practice ayurvedic medicine, which</p>	<p>Diet and Fasting</p> <ul style="list-style-type: none"> <li>• Most Hindus are vegetarians, including no eggs.</li> <li>• Fasting is common during festivals, but not expected of patients.</li> </ul> <p>End of Life Care</p>



	<p>encompasses all aspects of life, including diet, sleep, elimination and hygiene.</p>	<ul style="list-style-type: none"> <li>• Death is generally accepted philosophically. A Hindu priest will assist in this process.</li> <li>• Rituals include tying a thread around the neck or wrist of the dying person, sprinkling them with water from the Ganges River, or placing a leaf of basil on their tongue.</li> <li>• After death, do not remove sacred threads or wash the body.</li> </ul>
<p><b>Buddhism</b></p>	<p>Siddhartha, a royal prince born in 6<sup>th</sup> century BC, left his palace to search for truth. While under a banyan tree, Enlightenment, became known to him. Happiness came from changing self from within. He was then known as Buddha. Nirvana can only be attained through an absence of desire, achieving perfection, and lack of unique identity. Many Buddhist beliefs are derived from Hinduism.</p>	<p>Diet and Fasting</p> <ul style="list-style-type: none"> <li>• Belief in reincarnation demands a vegetarian diet.</li> <li>• Because fasting varies with the different schools of Buddhism, patients should be queried about special needs.</li> </ul> <p>End of Life Care</p> <ul style="list-style-type: none"> <li>• Buddhists monks should be consulted to offer spiritual support.</li> <li>• A shrine to Buddha may be placed in the patient’s room. Time for meditation at the shrine is important and should be respected.</li> <li>• “Mindfulness” is an important state of being. Patients may refuse medications (such as opioids) because they may alter alertness.</li> <li>• Buddhists generally accept death.</li> <li>• After death, a monk may recite prayers for one hour. The prayers need not be said in the presence of the body.</li> </ul>



## Readings on Understanding Spiritual Care

Alexander, Eben, M.D. *Proof of Heaven: A Neurosurgeon's Journey into the Afterlife*. Simon and Schuster, 2012. This book is crafted with the skill of an excellent mystery novel writer: one detail after another is carefully laid down to provide us with the clues we need later to understand how seamlessly the whole series of events tie together. Dr. Alexander contracts meningitis, a potentially deadly disease which he had treated many times in his own patients. But his case was an extremely challenging one, and the resolution of the disease is full of surprises. A beautiful book.

Benson, Herbert, with Marg Stark. *Timeless Healing: The Power and Biology of Belief*. New York: A Fireside Book, Simon & Shuster, 1997. The author of *The Relaxation Response* presents evidence from scientific studies that we have the power to heal ourselves. His studies also reveal that a large percentage of the American public believes in a higher power, and believes in the possibility of spiritual healing.

Berman, Phillip L. *The Journey Home: What Near-Death Experiences and Mysticism Teach Us About the Gift of Life*. New York: Pocket Books, 1996. Moving stories of people who have been near death but been revived.

Borysenko, Joan. *Fire in the Soul; A New Psychology of Spiritual Optimism*. New York: Warner Books, 1993. Borysenko shows how we can integrate those things that have wounded us most deeply and transform them into a life-view that is positive and uplifting. Transformative!

Burpo, Todd and Lynn Vincent. *Heaven is for Real: A Little Boy's Astounding Story of His Trip to Heaven and Back*. HIFR Ministries. 2011. Todd Burpo is a minister and the father of Colton, who almost dies, and does have a near-death experience. Colton's parents are ill-prepared to handle the information that Colton tells them in his innocent way, or to face the skepticism that is engendered in the small mid-western town where Todd has his church. This is the book the movie was made from.

Coberly, Margaret, Ph.D., RN. **Sacred Passage, How to Provide Fearless, Compassionate Care for the Dying**. Boston and London: Shambhala, 2003. Through anecdotes about the final trajectories of patients she has known, the author provides an introduction to the Buddhist view of death and dying. Dr. Coberly helps translate the Buddhist set of spiritual beliefs into a series of discussions to help people with a Western spiritual upbringing. This book could be read as a companion to *The Tibetan Book of Living and Dying* by Sogyal Rinpoche.

Dossey, Larry, M.D. *Recovering the Soul*. New York: Bantam Books, 1989. Dr. Dossey works on the premise that the mind does not exist within a body, but is "nonlocal," and is outside time and space. He explores evidence from medicine, religion, shamanism, and physics to provide a foundation for spirituality.

Halifax, Joan, PhD. *Being with Dying; Cultivating Compassion and Fearlessness in the Presence of Death*. Boston, Shambhala, 2009. A beautiful book full of wisdom and compassion. Dr. Halifax, a Zen Buddhist priest, has served on the faculty of Columbia



University, The University of Miami School of Medicine, and the New School for Social Research. She shows how meditation can provide strength for ourselves and for the dying patients who have been entrusted to our care.

Harvey, Richard. *The Flight of Consciousness: A Contemporary Map for the Spiritual Journey*. London: Ashgrove Publishing, 2002. This is a lovely guide to discovering who you are at the current point in your journey, and leading you to find ways to express who you can become.

Hopcke, Robert H., PhD. *There are No Accidents: Synchronicity and the Stories of Our Lives*. New York: Riverhead Books, 1997. Synchronicity is the study of how events that seem to happen by accident can have deep meanings in our lives, making us wonder whether they were, in fact, put there for a reason. A wonderful book.

Kelsey, Morton T. *The Other Side of Silence*. New York, Paramus, N.J., Toronto: Paulist Press, 1976. Kelsey provides a fascinating account of Christian meditation and cautions respect for its power. By leading you through accounts of the people in mystical orders, Kelsey gives a model for some of the purposes of meditation. If you decide to undertake a practice of meditation, you will find a firm foundation in this book.

Liebman, Joshua Loth. *Peace of Mind*. New York: A Signet Book, New American Library, 1946. Liebman was a Rabbi and scholar who had a gift for providing entry-points into mysticism through normal experiences. In looking at psychology, he finds pathways to spirituality. A lovely little book.

Magida, Arthur J. (editor), *How to Be a Perfect Stranger: A Guide to Etiquette in Other People's Religious Ceremonies*. Woodstock, VT: Jewish Lights Publishing, 1996. ISBN 1-879045-39-7 A guide for anyone who may be invited to participate in events in the life of people of a different faith. Provides information to help the reader understand the basic tenets of the faith, and how to dress, address the clergy, and participate without violating the religious practices or principles of their hosts.

Ring, Kenneth, M.D. *Heading Toward Omega: In Search of the Meaning of the Near-Death Experience*. New York: Quill, William Morrow, 1984. Dr. Ring has studied both the near-death experience itself and what happens after that experience to the people who have gone through it. This very readable, personal account is full of the moving stories told by those who have had a near-death experience.

Rinpoche, Sogyal, *The Tibetan Book of Living and Dying*, Patrick Gaffney and Andrew Harvey, Ed. Harper San Francisco, 1994. Sogyal Rinpoche is a Buddhist spiritual leader who describes the Buddhist guidelines for living, presenting this material in ways that are expressly geared for the American audience. It is a thought-provoking book, with insights and instructions on different stages of the death trajectory.

Zukav, Gary. *The Seat of the Soul*. New York: Simon & Schuster, 1989. A deeply nourishing book that leaps from physics into the spiritual. This book is the most beautifully grounding reading.



Zukav, Gary. *Soul Stories*. New York, New York: Simon and Schuster, 2000. These stories are touching and full of hope.

## Module Evaluation – Spirituality

Name \_\_\_\_\_ Date \_\_\_\_\_

What is the difference between spirituality and religion?

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How might you recognize that a patient wants a visit from the chaplain?

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What is the role of the hospice chaplain within the hospice team?

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What is a volunteer's role with regard to a patient's spiritual issues?

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Please write what you found most interesting during this module.

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Please describe any challenges or difficult issues that arose during this module.

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## Self-Care

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### Taking Care of Yourself

While we are taught to have “empathy” for our residents by keeping things in perspective and holding emotional involvement an arm’s length away, attachment does happen. It may be the length of time we care for some of our residents or simply part of the nurturing process especially if they have little support or presence from family and friends. Or it could be the



residents own engaging personality or dependencies that draw us in but the reality is that we do become attached.

In light of this, we need to actively support to one another. The best way to do that is the same as you do for families *just be there for each other*. Listen when someone needs to talk or even start the conversation if you feel a co-worker is sad. The facility may have a memorial service at regular intervals for staff to take time to remember the residents that have recently passed away. Community or palliative care organizations like Hospice or affiliated church ministers can help with this process and may be available to provide grief counseling as needed.

*So... don't hesitate*, reach out for help if you need it. Tell someone else how you are feeling. You are after all just as human as anyone else and involved in more than the average end of life experiences.

## Caregiver Burnout

The constant and prolonged care of a patient can take its toll on the caregiver in a cumulative fashion. Members of the interdisciplinary hospice staff are trained to watch for signs of caregiver burnout, providing support and guidance as needed. Volunteers can be key here, offering the caregiver respite time to take care of him/herself. In so doing, the caregiver can be better able to help the patient make meaningful decisions.

### The Three Stages of Caregiver Burnout

1. *Frustration*: The primary caregiver expresses continuing frustration and disappointment over the patient's deteriorating condition or lack of progress. The primary caregiver has difficulty accepting that the quality of care and effort have nothing to do with the actual health-related decline or mood of the patient.
2. *Isolation*: The primary caregiver struggles to maintain a sense of purpose in working so hard to provide care. S/he may express feelings of loneliness, being unappreciated, second-guessed, or criticized by other family members and the patient. The reality of the patient's condition and the limitations of caregiving are not accepted. The caregiver is reluctant, unable, or unwilling to reach out for help from others.
3. *Despair*: The caregiver feels helpless and adrift. S/he is unable to concentrate and loses effectiveness as a caregiver. S/he is no longer excited about the progress or response of the patient to quality care. As a consequence, the caregiver neglects personal care and well-being, loses interest in the community, social contact, and respite activities.

Take note if the patient's caregiver who you are helping starts to show the signs of burnout, and report it to the Volunteer Coordinator. These signs may include:

- Disrupted sleep patterns including insomnia or habitually oversleeping; never feeling rested even if the primary caregiver has had a full night's sleep; disturbing dreams or nightmares.

- Altered eating patterns, including either not being able to eat or overeating; significant weight gain or loss.
- Increased use of alcohol or drugs.
- Increased smoking or a strong desire to start again after having quit.
- Frequent headaches or sudden onset of back pain; increased reliance on over-the-counter pain remedies or prescription drugs.
- Irritability or impatience.
- The inability to handle one or more problems or crises.
- High levels of fear or anxiety.
- Overreacting to commonplace accidents, such as dropping a glass or misplacing something.
- Overreacting to criticism.
- Alienation and emotional withdrawal, even from the immediate family activities and those who offer relief and help. Feeling totally alone even when others are present.
- Feeling hopeless or trapped or thinking of disappearing or running away. Wishing simply “to have the whole thing over with.”
- Not being able to laugh or feel joy. Loss of hope, purpose, and meaning. Thinking of suicide as a means of escape.
- Overreacting with anger toward a spouse, child, or the patient. Resenting, neglecting or mistreating the patient.

**Note:** Neglect and mistreating the patient, as mentioned in the last bulleted section, constitutes abuse. Should you witness any patient abuse, or suspect it, Hospice Volunteers MUST contact hospice immediately to report your observations.

## Compassion Fatigue

As in caregiver burnout, compassion fatigue refers to the emotional, physical, and spiritual exhaustion that can occur to those who work in health and human services. Compassion fatigue is a one-way street in which individuals are giving out a great deal of energy and compassion to others over a period of time, yet aren't able to get enough back to reassure themselves that the world is a hopeful place. Over time, your ability to feel and care for others becomes eroded through overuse of your skills of compassion. You also might experience an emotional blunting—where you react to situations differently than you normally would. (See the list of signs of caregiver burnout).

*Preventing* compassion fatigue is really the key. As a volunteer, having supervision with the Volunteer Coordinator is imperative in order to process the dynamics that may occur with your patient and family. Other ways to prevent compassion fatigue include attending the monthly volunteer support group (during which you share your process) and coming to the ongoing educational trainings. Processing, getting support from the rest of the volunteer group, and





knowing when it's time to take a break can make all the difference in your emotional well-being and your effectiveness as a volunteer.

It's much easier to stop compassion fatigue from occurring in the first place than it is to repair things once it sets in. You have to continually practice good emotional health maintenance along the way and keep some sort of balance in your life.

## Taking Care of Yourself

Here are some time-proven ways to take care of yourself:

- **Pat yourself of the back** for communicating at the very highest level possible when you are with your patient and family. It requires tremendous skill and energy to ask the right questions, create trust, mediate, read between the lines, etc...all simultaneously.
- **Give yourself some time off.** Hospice volunteers need respite, too. Let the Volunteer Coordinator know when you need some time and distance.
- **Avoid judging or second-guessing your own reactions** when your patient dies. Crying doesn't necessarily mean over-involvement; not crying doesn't necessarily mean that you are uncaring.
- **Do not permit family and friends to put you on a pedestal** because you are a hospice volunteer. Some people might say "You, of all people, should be strong enough to handle this...after all, you work with dying people." But they do not understand what it is like to do your job, and that comment is actually belittling. You would not want to be so unemotionally attached that you do not respond to the death of your patient. And nobody else on the team would want you to be that way, either.
- **Don't worry about making mistakes.** Everyone can think of a time when s/he wishes s/he'd said or done something differently. Have compassion for yourself.
- Many times, it may seem as if you don't make a difference... but know that you are a vital member of the hospice team and **you do make a difference.**

## Ways to Nourish Yourself

There are many ways to nourish your spirit when you are working in an atmosphere of stress. These techniques fall into several different types:

- **Spiritual and religious practices:** the rosary, yoga, tai chi, relaxation techniques, meditation, chanting, or creating an altar or prayer corner....
- **Doing quiet activities:** arranging a bouquet of flowers, gardening, being present to nature, cooking a meal, reading....



- **Actively following a hobby** or one of your normal activities: bicycling, journal writing, recording dreams, playing a musical instrument, collecting rocks, sea shells, or feathers, sailing, swimming, writing poetry, exercising, singing, dancing....

Of course, there are countless other activities and practices that you may do for self care; the homework portion for this chapter provides an opportunity to name these supports. When you are being stretched by difficult tasks, it’s important to remind yourself of the many supports that you have, and to avail yourself of them.

### Stress Reduction – A Practical Approach

The practice of mindfulness is very portable. As long as you are breathing, you have the ability to become more relaxed and present. You can take it anywhere...and can provide grounding to allow you to be more present with your patient/family. The following introductory techniques of mindfulness provide tools for you to feel emotions without getting caught up in them.

#### Cultivating Awareness

**Practice #1:** Mindfulness is as close as your breath. It’s just that simple, but very powerful. Notice how you’re breathing right now: is your breathing short or long, steady or erratic? Where do you feel the breath the most? At the nose? In the throat? In the chest? In the belly? Allow yourself to follow the flow of your breath for one minute. Keep count of every time your focus wanders to a thought or an emotion. Then return to focus on breathing.

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Minute over? What was your count? 10? 20? 50? Can’t remember? Not uncommon. This practice gives you an opportunity to become aware of how constantly busy the mind can be. Chances are that the mind traveled far, and away from the breath. The untrained mind tends to do that. Often, we shift easily from thought or feeling to judgment without any awareness, until we’re in the thick of the “mindstuff” and away from the present moment. In this state, we are reactive. Things just happen to us without any awareness of having options. This attitude breeds a stress response.

#### Working with the Mindstuff

**Practice #2:** Observe the breath again for one minute. This time, if any thoughts or feelings come up, acknowledge the activity by softly saying in the mind’s eye -- “thinking” -- or whatever feeling it is (like “anger” or “anxiety,” etc.). Notice if any judgments arise from the “mindstuff.” Instead of allowing yourself to get carried away from the breath by the mindstuff, label the thought or feeling. Then gently but firmly, let go. Allow the focus to return to the breath. Do this as many times as the activity of the mind requires.

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Was there any difference between your experience in the first and second practice? Where **Practice #1** is an example of how unquiet the mind can be, **Practice #2** gives you tools to work with the mindstuff. By not clinging to the mindstuff, you give yourself the opportunity to return



the focus to the breath. Breathing mindfully allows you to shift from being caught up in a wave of constant mental activity, to being aware of the mental activity, to simply being in the moment.

It's possible to feel whatever comes up without having to *do* anything. Practicing mindfulness does not negate thoughts or feelings; rather, it creates space to acknowledge and accept whatever comes up, but without judgment. This allows you to be in the present, as opposed to dwelling on regrets of the past or fears about the future, which tend to breed stress. In this way you can be, and are, peaceful.

## Don't Be Shallow

**Practice #3:** Nourish yourself through deep three-part breathing. To completely fill your lungs, do it as you would fill a glass with water; from the bottom on up. As you inhale, expand the abdomen, then rib cage, and then upper chest; as you exhale, contract the upper chest, rib cage, and abdomen. Get comfortable with this practice, and add a count to keep the breath even (i.e. as you inhale, silently count 1, 2, 3, 4,5... and exhale to the same count). Practice this for two minutes.

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Since it's a common western trait for people to suck in their stomachs, ballooning out the abdomen upon inhaling might seem strange indeed. But breathing deeply in this way helps to short-circuit a stress reaction.

Learn from babies: If you watch a baby at rest, you will notice that babies breathe naturally and deeply from the belly. When we're stressed, the abdomen becomes tense and the breath becomes shallow, rapid, and chest bound. We deny ourselves oxygen, the very substance we need to exist from moment to moment. Three-part breathing allows us to take oxygen into our lungs deeply, and exhale carbon dioxide from our lungs fully. Note that the emphasis is on an even exchange between inhalation and exhalation; normally, we only exhale a fraction of what we inhale, so this practice gives us an opportunity to let go.

Deep three part breathing both calms the nervous system and refreshes dulled senses with an infusion of more oxygen to the blood stream. It's a wonderful way to complete mindfulness Practice #2, taking the breath into your control and preparing you to transition back to the activities of the day.

## Homework Assignment: Self Care

### Supports In My Life

It's so important that our hospice volunteers have good balance and support in their lives in order to stay healthy (and not burn out). Take a moment to identify the people, groups, and activities in your life which form your network of support. Please put a star next to whomever or whatever is the most important source of support and comfort. How often do you devote time to being with/doing those specially denoted areas that help to give meaning to your life? Are there any changes that you might consider making, allowing you to accept more support?



## **What is important to me**

Family Members:

Relatives:

Friends:

Neighbors:

Teachers/Counselors:

Colleagues:

Clergy:

Pets:

Clubs or Church Groups:

Volunteer Work:

Job/Work:

Educational Activities:

Athletic Activities:

Art/Music:

Other:

Favorite Belongings:

Areas for self-care that I'd like to develop:

## Readings on Self Care

Moore, Thomas. *The Re-Enchantment of Everyday Life*. New York. Harper Perennial, 1986. Dr. Moore looks at those every-day things that can nourish our internal lives, and presents them to us so we may see them in a new light. A lovely, lovely book. Both richly scholarly and deeply nourishing.

Remen, Rachel Naomi, M.D., *My Grandfather's Blessings; Stories of Strength, Refuge, and Belonging*. This wonderful book tells us that helping others is the way to heal ourselves and guides the reader to an understanding that the blessings contained in life can give us the courage to live a fulfilled life



Remen, Rachel Naomi, M.D. *Kitchen Table Wisdom; Stories that Heal*. New York, Riverhead Books. 1994. Dr. Remen is the cofounder of the Commonwealth Cancer Help Program, and brings her depth of multidimensional healing knowledge to a prescription for everyday living. This is a book filled with life, light, and grace.

Moore, Thomas. *Care of the Soul: A Guide for Cultivating Depth and Sacredness in Everyday Life*. Harper Perennial, 1992. Dr. Moore talks about the “myths” of our lives... that is, the way we tell ourselves stories in order to better understand what is happening to us. He is an excellent story-teller, finding exquisite ways to illustrate how we can find depth and meaning in our lives.

## Module Evaluation – Self Care

Name \_\_\_\_\_ Date \_\_\_\_\_

List some ways you can recognize caregiver burnout.

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What can you do if you notice that somebody is exhibiting caregiver burnout?

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What is compassion fatigue? Name some ways you can prevent compassion fatigue.

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What are your favorite ways to de-stress?

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